

MASTER OF SCIENCE BY RESEARCH

**The experiences of intensive care patients while being attached to a mechanical ventilator and in a conscious state
a qualitative exploratory study**

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Dissertation title:

The experiences of intensive care patients while being attached to a mechanical ventilator and in a conscious state: a qualitative exploratory study.

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Abstract.

There is a deficit within the research, in England, regarding the experiences of patients nursed within a critical care environment over a long period of time and who are conscious when connected to a mechanical ventilator. This new, qualitative study had the aim of exploring the experiences of intensive care patients while being attached to a mechanical ventilator and in a conscious state, in order to identify implications for nursing practice, policy and future research. After ethical scrutiny and approval by the Coventry University research ethics systems, an NHS Local Research Ethics Committee, and a local NHS trust research and development committee, 6 participants were recruited for participation in semi-structured interviews. All participants had spent at least 14 days on a ventilator and all had tracheostomy tubes inserted during this period of time. Thematic analysis produced findings which are reported in six interdependent themes as follows:

- The centrality of family visitors' presence and social support within patients' critical care experiences.
- Losing your voice: unresolved communication difficulties.
- Difficult thoughts and feelings associated with physical, personal care by health professionals.
- Asleep or awake? Vivid, violent, confusing and disturbing dreams.
- A noisy and disorientating environment.
- Vulnerability and loss of control over body, mind and identity.

Findings are discussed in order to identify implications for further research, policy and nursing practice. Specifically, the significance of this study for nursing practice in

relationship to effective communication with patients, the importance of reflexivity about power in nursing practice and recognition of the key role of the family in providing advocacy and social support for patients, are emphasised.

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1. Introduction.

The influence of evidence based medicine is now at the forefront of medical and nursing care in the United Kingdom, with the result that physiologically based protocols now guide much nursing practice. In particular, standardised care, based on current Department of Health NICE guidelines, is influential. However, such protocols are often based on a biomedical model of health which focus on treating specific illnesses and hence are often prescriptive in approach. Indeed, many protocols do not incorporate the patient experience. In response to this context, the Department of Health published the 'Patient and Public Involvement' (DH, 2004) document which advocated patient involvement and suggested how feedback can be used to enhance patient care. In addition, the Darzi Report (DH, 2008) confirmed the related importance of dignity, compassion and respect for patients within their healthcare experiences. Understanding patients' experiences is a vital starting point in demonstrating dignity, respect and compassion. Therefore, this exploratory and qualitative research study addressed these important policy and practice issues by specifically capturing the personal experience of non-sedated, conscious patients who were cared for within an intensive care environment while connected to a ventilator.

Within the field of critical care, the biomedical model of health is dominant, not least because the focus of treatment and care is multi-organ failure, including heart failure, respiratory failure, renal failure and other major organ failures. Much of the treatment and care is based around the artificial support of vital organs using drugs, machines and involves fine tuning biochemical markers to optimise the patient's chance of survival. This focus is crucial if patients are to survive an acute life threatening stage of illness. At this stage patients are fully sedated with the intention

of them being comfortable and often unaware of what is happening to them. Some patients make a swift and full recovery, but for other patients recovery can be slow and prolonged. This is often because they continue to have a degree of respiratory failure and require some support from a ventilator. In such cases patients will usually have a tracheostomy tube inserted and sedation will be discontinued in order to maximise and strengthen their own respiratory effort. Consequently patients are conscious and aware for the duration of their remaining stay in critical care.

When patients are in this latter, less acute life threatening stage their condition may be more stable and their biochemical markers will have returned to normal parameters. Indeed, most patients will have normal heart rates, blood pressure and kidney function. However, their lung function may take longer to recover requiring support from a ventilator in order to breathe adequately. Such patients no longer require sedation and are awake and orientated, many watching television or perhaps reading. This study examines the patients' experience of being cared for within an intensive care environment when they are conscious and connected to a mechanical ventilator.

The structure of this dissertation is as follows. First, the background evidence within the literature is discussed, followed by specification of study aim and objectives, discussion of methodology and presentation of findings. This is followed by discussion of the significance of findings in relation to previous research and identification of implications for policy, nursing practice and future research. However, the next section of this dissertation discusses and analyses the results of the literature review which provides the background underpinning this study.

2. Background: literature Review

One of the catalysts for this study was an article entitled '*The View from Bed Number Ten*' (Baier, 1996) written by a patient regarding their critical care experiences. This paper was written as an autobiographical account by a woman, nursed within a critical care environment for eighteen weeks, in the United States. The author emphasises her sense of loss of control and almost total dependency on others to meet all her needs. Baier (1996) also discussed the frustration of not being able to communicate, how nursing staff would talk over her, talk about her or exclude her. For Baier, her husband and family played a vital role in her recovery. In this paper the author *demands* that critical care nurses look, listen and consider the critical care environment and the nursing care provided, from a patient's perspective. In contrast to this subjective but important account, a systematic review of the research literature regarding patient experiences in intensive care units, over a thirty year period, was undertaken by Parbury (2000). Parbury identified key themes related to patients' experiences including: impaired cognitive functioning, disturbing dreams, sleep deprivation, pain, difficulty in communicating needs, frustration at not being able to talk, loss of control and dependency. This review of literature explores some of the questions raised by these papers in more depth. Initially the methods employed and the themes identified within this process are examined.

Literature search, inclusion criteria, appraisal and development of themes.

After Aveyard (2007) four possible ways of searching for the background literature were considered. Those methods were, first, using online computer databases, which

was the most useful and primary method. In addition, second, searching the reference lists of important papers was undertaken. Third, relevant journals regarding patients' experiences of intensive care were searched, but no single journal elicited much more material than others. Fourth, journal abstracts were examined to gain insight into the aims, focus, methods, analysis and findings within papers. This was a particularly useful process, especially when combined with examination of reference lists within those same papers. However, as Carnwell and Daly (2001) have advocated, seeking the help of specialist librarians within Coventry University and my employing trust library was also invaluable and should be noted.

The online databases used were important, but it was necessary to understand their strengths and weaknesses and also to recognise that using more than one database was essential to avoid disciplinary, ideological or professional partiality within those resources (Aveyard, 2007). The following databases were employed and found to be valuable: CINAHL which provides information about nursing and allied professional literature; MEDLINE the main source of biomedical literature; the Science Citation Index which accesses literature on sciences, including social sciences; ASSIA the social science database; PSYCLIT the psychology databases and the Cochrane Library with access to systematic reviews.

Initially, before an in-depth search of the journals, a preliminary mind map was developed to establish the scope of possible search concepts and synonyms. As the search developed over time the key terms were refined to those that were most able to assist in accessing the literature relevant to the study aims and objectives. Those key terms were: critical, intensive, care, therapy, nursing, patient experience, lived experience, patient knowledge, patient attitudes, family, visiting, dreams, delirium,

sleep, pain, noise, environment, communication and tracheostomy. Various combinations and synonyms of these key terms were used to help identify a variety of journal papers for possible inclusion. However, it was also important to be clear and explicit about the inclusion and exclusion criteria to be used within the search strategy (Silverman, 2010). The inclusion and exclusion criteria needed to be clear, concise and well defined to ensure that the study remained focused and the search did not become hindered by literature not relevant to the review (Aveyard, 2007). These criteria also needed to be transparent in order to ensure that decisions to include or exclude are based on sound judgements (Carnwell and Daly, 2001) and to enable supervisors to assess and provide feedback on these decisions. The specific inclusion criteria identified were that papers must be evidence based research of good quality, that those papers must be published and hence have undergone the peer review critical process. Publications to be included were those published since 1980. This is a long time frame but necessary to maintain the primary focus on patients' experiences rather than technological or medical or clinical developments in intensive care. In addition, papers had to be published in English as there were no resources to translate papers. Furthermore, there was a desire to include papers from societies with modern healthcare systems, where intensive care systems may be comparable to the setting for this study. Exclusion criteria were specified as unpublished journal papers and the grey literature, where peer review may not have been undertaken before publication, studies not written in English and articles published before 1980.

The same search strategy was applied to all the databases using the key terms. All use of databases and employment of other search methods produced thousands of papers, initially, but the search was narrowed, within the online databases specifically, by

combining key terms using Boolean operators such as 'and' and 'or'. However, as the fieldwork began and initial data analysis commenced the search was expanded again, in order to inform the analysis of new unanticipated study findings. After reviewing the title of the papers, most were excluded if the title was not related to the subject area. In reviewing the abstracts and reading the papers as a whole the papers appraised in the themes below were identified.

The framework chosen to assist the evaluation of the papers, identified for the review of the literature here, was the Critical Appraisal Skills Programme (CASP) tools which were developed by the Public Health Resource Unit. CASP was chosen as it enables individuals, like myself a novice researcher, to develop the skills in making sense of research evidence and helping transferring knowledge into practice (Public Health Research Unit, 2010). The CASP tools can be used to analyse different types of studies, including qualitative studies which was particularly important for the empirical study reported here. The CASP tools are also valuable in that they offer a useful series of interdependent questions to assist interrogation of differing kinds of research (Public Health Research Unit, 2010).

Carnwell and Daly (2001) have suggested that a literature review should identify distinct themes which emerge from the reading of the literature itself. This was undertaken, reported and assessed within this department at the University of Coventry. The literature was reviewed, summarised and synthesised, however, the themes within the literature, reported in this chapter, were also influenced by primary data collection and confirm the iterative nature of the research process as a whole. As data emerged within the fieldwork process, further examination of the literature

was required. This resulted in a re-evaluation of particular themes and indeed elimination of others within the initial literature review. An example of this is the theme regarding disturbing dreams and unreal experiences. Although studies identified that patients may sometimes experience dreams (Granberg, 1999, for example), when analysing the empirical data it was evident that the experience of disturbing dreams was a more important feature of the participants' experiences than anticipated. Disturbing dreams was the first thing all participants talked about. In contrast, intensive care patients' experience of pain is often featured in the literature and was a theme that emerged from the initial literature review. However, when analysing the study empirical data this theme did not emerge as significant and is therefore not analysed in depth here. The key themes emerging from the iterative literature review process are now discussed. The seven themes are empowerment, the importance of family, dreams and unreal experiences, personal care, tracheostomy, communication and sleep disturbances.

Empowerment.

Traditionally healthcare had been delivered within a paternalistic paradigm which professionals hold much power. This paternalistic paradigm is often associated with a bio medical model of health where the 'doctor knows best' (Hewitt-Taylor 2004). Similarly, nursing could be described as maternalistic in approach, with the patient as the passive participant in the relationship between women professionals and patients. However, in the United Kingdom in the 1980's, the concept of empowerment within healthcare became more influential. This development was linked to influence from the wider consumer movement in civil society, which culminated in a key document

‘Patient Choice’ (DH, 1986b). Indeed, by 2003 the Royal College of Nursing’s definition of nursing also included the nurses’ role in the facilitation of patient empowerment (RCN 2003).

The concept of empowerment is used in diverse ways, influenced by perspectives and ideologies within educational, organisational, environment, sociological, psychological and feminist disciplines and theories (Rodwell, 1996). For the purpose of this study, which focuses on intimate and routine relationships between patients and professionals within intensive care, the following psychological definition is most apt:

“Empowerment is therefore seen as a process of transferring power and includes the development of a positive self esteem and recognition of the worth of self and others.”
(Rodwell, 1996, pg23).

Previously, Malin and Teasdale (1991) had discussed the tension between empowerment and caring. The concept of caring has strong links with notions of altruism but also, at the same time, control and paternalism where the relationship between nurse and patient may be unequal. In contrast, the aim of the relationship between nurse and patient from an empowerment perspective is one of a partnership. Moreover, empowerment here also implies a therapeutic relationship, based upon mutual respect, trust and equality of worth. Hewitt-Taylor (2004) suggests that this latter understanding of empowerment as being the opposite of a paternalistic approach to healthcare.

Within the context of intensive care, specifically, Christensen et al (2007) identified that empowering the critically ill patient does present specific challenges for nurses due to the nature of their illness. The majority of patients in the initial stages of critical illness are fundamentally 'disempowered' in that they are totally dependent on both technology and healthcare professionals. As a patient's condition improves they become less dependent and, in time, gradually gain independence from technology and professionals. This is a gradual process and nurses have a major role in enabling a patient to regain control of both physical bodily functions and the psychological attributes of self esteem, and memory recall. An earlier conceptual paper by Rodwell (1996), however, examines the potential positive implications for self esteem and a sense of hope, in re-establishing a sense of control for patients that is associated with an empowering approach .

Wahlin (2006) undertook a valuable qualitative phenomenological study, with eleven participants, to explore the concept of empowerment as it was lived and experienced by intensive care patients. This study identified how critical care nurses can empower their patients, during the recovery phase, by tapping into what motivates and stimulates the patient's own inherent joy of life. Wahlin (2006) discusses how important it is to explore with patients what motivates them, as this is linked to their inner strength and fight for survival. In addition, this process of empowerment, was found to be achieved by talking to close family members and taking time to communicate with patients in the critical care setting however weak and vulnerable they may be. Within this study the inclusion criteria was participants who had only been in intensive care for a minimum of three days. Indeed, 9 of the eleven

participants were in intensive care for ten days or less. For some participants their incapacity and dependence may have been temporary, which is a study limitation in that my own study reports on the experiences of long term patients.

Watson (1979) has also argued that by demonstrating that care about the individual is important to the nurse may result in increased levels of hope in the critically ill patient. The concept of hope can be conveyed implicitly and explicitly by nursing staff: implicitly by ones own personality, approach and demeanour, or explicitly by ensuring a caring manner is central to ones nursing practice (Cutcliffe 2002). Within critical care, the link between caring and how it affects patients' notions of hope and self worth can also be extended to how a patients' family may be treated by nursing staff. In Wahlin's study (2006), again, patients were found to be sensitive to the attitudes of the staff. Two different examples are used to illustrate the point. The first discussed how a patient felt he was a nuisance and felt rejected when a nurse was unwelcoming to his visitor. The second example relates to how a nurse spontaneously noticed a patient's needs and responded positively. This made the patient feel valued and significant as an individual.

Much of the above literature is important but takes medical or professional notions of empowerment as its starting point. However, social scientists have raised concerns about the ways in which medical power has become increasingly influential in both everyday life and health. For example, Beck identified the expansion of the medical domain to expand the numbers and scope of risks and hazardous conditions in human societies (Beck, 1992). Illich's (1976) earlier work emphasised the ways in which medicine may harm others through iatrogenesis. Michel Foucault's (1997) work is

also influential. Foucault argued that, within healthcare, the relationship between medical power and knowledge could not be separated, these two areas being interdependent at the micro level of all everyday interactions. Hence Foucault wrote about 'knowledge/power' within which surveillance and control of patients could be achieved. One aspect of this was the link between seeing, surveillance and power over docile bodies. The clinical gaze of the medical professional is understood as a penetrative form of observation. Henderson (1994), informed by Foucault, suggested that intensive care nurses' role in knowledge/power is important to consider. Over time intensive care nursing, influenced by rapid technological changes, has been involved in forms of surveillance, as Foucault suggested. Within the intensive care unit, the body is the object of enquiry within which the observation 'chart', a document which records and informs the care of individuals, is important (Henderson, 1994). My experience indicates that some nurses sometimes joke that they are 'nursing the chart, not the patient'. Henderson (1994) reported that the observation and consideration of the emotional status of the patient is not given a high priority unlike the 'chart'. My experience, again, has been that the 'chart' does not necessarily meet all patients' needs because it is designed to meet the needs of an *acute* critically ill patient, not the needs of the awake, *long term* patients has investigated in this study. Henderson (1994) also found that the process of using the 'chart' invented a new patient, a kind of 'recorded body', where much is known about the physiological but little is known about psychological wellbeing. This process is contradictory, in my practice experience, in that it may prevent a more meaningful relationship between nurse and patient but does enhance communication with medics and other professionals where knowledge/power may be shared.

More recently the conceptual focus of social research has been linked to the medicalisation thesis. Conrad (2004 & 2005) is one of the key proponents of the medicalisation thesis, emphasising that the development of new technologies has intensified the process whereby medical influence and power over health, identity and culture expands. Healthy processes become medicalised within a dominant biomedical approach. Conrad (2005) argues that one of the problems of medicalisation is that wider factors (identity, family, community) may be marginalised within analysis and technical, rational power and knowledge are assumed as the most valuable components. In many ways intensive care units are one of the most medicalised settings within in our society, where patients who are conscious may have so little control over their lives, their bodily functions and their contact and relationships with others. Indeed, when I began this study I was most interested in investigating patients' experiences of 'weaning', that is reducing the amount of support a patient receives while connected to a mechanical ventilator. However, the study findings identified that 'weaning' was not an important issue for participants interviewed.

Bury (2005) has argued that the medicalisation thesis may be exaggerated or even have a conspiratorial sense in that it may underestimate people's capacity to resist the power and influence of health professionals. In particular, relatives may play a part in empowering patients, sometimes acting as their advocates. For example, Wahlin (2006) found that some patients felt safer when their close relatives were around and for others their presence gave them strength in difficult times. The important role of family members, in this respect, will be considered next.

The importance of family.

The importance of having close family members visiting regularly and remaining in close proximity to patients has been identified as important following critical illness. In a recent phenomenological study involving ten patients, (Engstrom and Soderberg 2007), critically ill patients felt that having close family members visit was as important as the life support machinery. The aim of this particular study was to explore the meaning of close relatives for people who have been critically ill, in intensive care and who had been mechanically ventilated for longer than twenty four hours. Although this study also looked at the relationship participants had with close relatives following critical illness, it is clear that the positive impact of their presence at the bedside during the participants' critical illness phase was significant. The presence of family made the patient feel safe and reassured them that someone was there for them. Family visiting was also seen as important because some patients encountered delusional dreams and nightmares where horrific things seemed to have happened to their family and as these patients were unable to verbalise, regular visits provided reassurance that family members were safe. Engstrom and Soderberg (2007) also found that having close family members visit, or even having their photographs close by, was sometimes the only thing that kept the critically ill person from 'giving up'. This proximity of close family enabled the patient to find the willpower and the strength to carry on, sometimes because the patient felt that they did not wish to fail the family that cared for them. This (Engstrom and Soderberg 2007) study is an interesting one in relation to this current study, although only 10 people were interviewed and hence there is limited opportunity for generaliseability of findings. However, some participants were only on intensive care for a minimum

of 24 hours, whereas this study examined the experiences of participants whose minimum length of stay was 14 days. Engstrom and Soderberg (2007) recruited 5 participants using intensive care nurses working with patients, raising questions about possible coercion within recruitment. Furthermore, their study was undertaken 18 months after discharge from intensive care, which may help us understand the long term significance of their experiences, but there is also a risk that the participant's memories may also have been influenced by family members' accounts over a period of time. The study reported here analyses participants' experiences while patients were still in hospital but outside of the intensive care environment.

Hupcey (2001)'s important study explored the quality of social support as perceived by 30 participants who had been critically ill. This descriptive study identified that the majority of participants during the critical phase of their illness relied on only one supportive friend or family member. Once they were more stable, they enjoyed seeing other family members and friends. What constituted good quality support for most participants was having someone emotionally close to them who they did not have to interact with or entertain and whose presence was important in itself.

Potential participants were chosen by intensive care staff who selected them as having adequate social support from visitors or, in contrast, as lacking social support. The length of time the participants were nursed in intensive care was not identified, a limitation that is important as this would have had some bearing on the amount and type of social support they required if they were long term patients within intensive care. In addition, interviews were undertaken within the intensive care department where issues of vulnerability and power are acute. Nevertheless, the importance of social support for patients is not to be underestimated. An older study, Toombs

(1993), found that the onset of critical illness is accompanied by acute awareness of the unpredictability of life and, in particular, found that patients require a great deal of emotional support,.

McKinley (2002) highlighted a further important contribution that family members may offer, conducting focus group interviews with 14 participants, 3-6 months following discharge from intensive care. This study identified that family members were able to explain the sequence of events leading up to the time of the interviews being undertaken and provided many missing links created by patient's own experience of memory loss, due to sedation, at this difficult time. Often it had been family members who had accompanied the participant throughout their illness and were therefore able to help place the participant's current situation, in intensive care, into some context for them. This supplemented the patient's feeling of security (McKinley 2002). Focus groups are valuable for examination of shared, collective views and experiences but may not be the most effective way of gathering in depth, rich data about individual's experiences. However, there was no in depth analysis of focus group dynamics and process which is important to consider with this collective approach towards data collection. Furthermore, the timing of interviews, 4-6 months after discharge, may also be a limitation in that findings indicated that some participants remembered very little about their experiences.

It is important to note, at this point, that in my professional experience one related issue that remains frustrating for patients, and challenging for relatives and critical care health workers, is that the position of the tracheostomy tube lying below the vocal cords prevents patients from speaking. During critical illness people

sometimes use family members as forms of support for communication. Often family members interpret on behalf of the critically ill person and patients may wait until relatives are present in order to make their needs known. This issue will be considered in more depth later in this chapter, but the next theme focuses on dreams and unreal experiences.

Dreams and Unreal Experiences.

In an clinical study by Rundshagen (2001) 289 patients were interviewed using a series of structured questions 48-72 hours after discharge from critical care. The aim of the study was to identify whether patients' remembered any events before regaining consciousness. All patients were either intubated prior to admission to critical care or intubated and sedated on arrival. Although approximately half of the sample were discharged to a ward within the first twenty four hours, the findings for the remaining patients indicated that the longer they were sedated and ventilated the more likely they were to remember dreams and unreal experiences, and some participants experienced nightmares. Rundshagen's (2001) work involved a structured interview which closes down the scope for participants to explore their experiences in their own terms in more detail. Indeed, the study focused on recall by participants but did not examine how participants felt, thought and responded to these difficult life experiences. Although this was a larger sample than other studies examined in this chapter, 233 of these patients were elective post-operative admissions. This means that their stay in intensive care was a maximum of 7 days, and they were only sedated for a maximum of 4 days. In this study 187 participants remembered little about their intensive care experiences. Nevertheless, earlier work reinforces the importance of dreams, displaced memories of reality and unreal

experiences, during and following patients' time spent in intensive care (Pattison, 2005). Another small study (Laitinen, 1996) involving ten participants examined patients' experience of intensive care following cardiac surgery and found, that dreams and unreal experiences were important whilst a patient was on the threshold between awareness and unawareness.

According to Granberg (1999) for many patients, unreal experiences are, at the time of their appearance, understood as real but later labelled as fantasies or dreams.

Granberg (1999) intended to record the deeper meanings of patients' experiences and also examine their memory recall during and after their intensive care stay. Using a sample of 19 patients, Granberg (1999) found that the psychological trauma of being ill compounded the confusional state of many patients. This study is valuable in that participants were studied longitudinally with interviews at 6-10 days post intensive care discharge and then again at 4-8 weeks after discharge in their own homes. The latter setting may have been particularly useful in allowing participants to explore, critically, their experiences outside the medicalised environment of intensive care or the hospital. Unfortunately, the recruitment strategy, within the published paper, is unclear. There is, however, usefull discussion of reflexivity and the researcher's potential bias. But the participants had not spent a lot of time in intensive care, with a minimum of 36 hours in some cases, which is limited when considering the experiences of some intensive care patients and also limited when compared with the participants selected for the study reported in this dissertation.

Roberts and Chaboyer (2004) explored the experiences of dreaming by 31 participants in intensive care 12-18 months after discharge, in order to examine the nature of

unreal experiences, dreams and types of dreams. They found that, for some people, dreams could be violent, persecutory and disturbing, and, for others, they could be reassuring and include themes such as divine experiences and familiar faces in unfamiliar surroundings. Data was gathered by telephone interviews 12-18 months after discharge which, even the author indicates is a disadvantage, not least because the use of face to face interviews to gather information about thoughts and feelings would have been potentially valuable in providing in depth accounts. The length of stay of participants in intensive care in this study was only 72 hours. However, the findings from this study are important because 16 of the individuals interviewed had shown no sign of 'agitation' in a previous ethnographic observation study by the authors, yet of these 16 participants 11 reported that they experienced disturbing dreams. Roberts and Chaboyer (2004) concluded that there was no correlation between dreams and agitation which may be important in practice for observers, , such as nurses and family members.

Closely linked to the phenomenon of dreams and unreal experiences is the clinical state of delirium. Sedated, mechanically ventilated patients are at high risk of developing delirium. , Until recently, any existing recognised formal assessments to confirm this latter condition have not been appropriate for use with patients in critical care because they require patients who can communicate verbally (Ely et al. 2001). However, the Confusion Assessment Method (CAM) test is now being piloted in the intensive care unit where this study was undertaken. This process, called CAM-ICU, can be used by critical care personnel without expertise in psychiatry to assess patients' levels of confusion or delirium within intensive care settings specifically (after Ely et al. 2001). The CAM-ICU tool may be useful as there is evidence that

some patients will go on to develop post traumatic stress disorder in the months that follow their critical illness (Jones et al., 2001). Indeed, recent NICE (2009) guidelines recommend that the focus of both critical care medical and nursing interventions must include the physical and psychological rehabilitation needs of patients who have been critically ill.

Personal Care: Privacy and Dignity.

There is limited research regarding patient experiences of receiving personal or intimate care in critical care units, or within the hospital environment generally, in specific relation to privacy and dignity. The necessity of ensuring a patient's privacy and dignity is incorporated into the Nursing and Midwifery Council Code of Professional Conduct (NMC, 2008). In addition, the Department of Health introduced the *Essence of Care Pathway* (DH, 2001) which incorporated privacy and dignity as a standard to be achieved through a benchmarking process. The aim of this policy is to provide nursing care that is focused upon respect for the individual. Incorporated into this model are seven areas for consideration which include health care workers attitudes and behaviour towards patients, understanding patients' individual needs, respecting personal space or boundaries, confidentiality, modesty and appropriate and effective methods of communication. In 2006 the Department of Health (DH, 2006) conducted a simple online survey, which encouraged both health care providers and recipients and their families to describe their experiences of good and poor practice in relation to dignity. Approximately 400 responses included examples of good practice where dignity was preserved. There were also examples of undignified care. Such examples included people being left in soiled beds or clothing and not being given assistance with eating and drinking. However, in depth

qualitative research into the meaning of dignity, within intensive care, and how dignity is enacted is limited.

Walsh and Kowanko (2002) undertook a qualitative study and found that, within nursing practice, the word dignity is frequently used but seldom defined and understood. Their small phenomenological study explored both nurses and patients perceptions of what dignity actually meant. Both groups were asked to describe instances where dignity had been maintained or compromised. They interviewed 5 patients and 4 nurses and found that there was a strong correlation between what nurses and patients understood by dignity, including privacy of the body, consideration of emotions, respect, confidentiality and discretion about elimination. Nurses felt that the hospital environment and time pressures were not always conducive to the preservation of patients' dignity. The study was small, and employed the method of seeking volunteers to be participants which limits the validity of findings. This is significant because often it is the incapacitated and most vulnerable who are more likely to experience situations which are undignified, and such patients may not be in position to respond to invitations for involvement in research. There is no information within this paper about nurses' experience or training, nor does it identify the capabilities and knowledge of patients. An observational study may have provided additional triangulated evidence to support this study because what participants (nurses) say and do may not be always consistent.

Whitehead and Wheeler (2008) examined what patients understood by privacy and dignity within a questionnaire administered to 40 patients, with quantitative and qualitative elements included. They found that dignity and privacy were very

important to patients and highlighted areas, within the clinical environment of a mixed gender ward, about how a patient may feel compromised. The study used a questionnaire to obtain data, but its convenience sample was purposive as opposed to relying on volunteers. This research may be relevant to the critical care context as both male and female patients are nursed in open plan areas and there may be no side rooms, (which is common of many critical care units within the United Kingdom). The opportunity to interrogate patients' experiences in depth was not possible using this quantitative methodology, and there was no specific focus on experiences in intensive care.

A grounded theory study by Billings et al. (2009) does not focus on intensive care patients' experiences specifically, but is worth noting because it focused on the maintenance of dignity associated with continence issues, which is important for critically ill patients. Their study recruited 33 older people resident in hospitals or nursing care homes. They identified that dignity was preserved when individualised care was given consistently and discretely by the same person. Furthermore, they identified that people cope when they feel their dignity may be compromised by suspending their personal concept of dignity as they know that their current experience is only temporary. Although most of the available literature regarding privacy and dignity in relation to personal care is focused on the elderly, the findings may be transferable, in some respects, to patients in critical care who are a particularly dependent and vulnerable group of patients. Within the critical care environment it is crucial that nurses recognise their responsibilities as advocates in maintaining privacy and dignity of the critically ill.

The use of a tracheostomy.

Providing the patient's condition is progressing, the benefits for the patient of having a tracheostomy are that it allows the important process of rehabilitation to begin. For rehabilitation to take place it is necessary that the initial acute phase of the illness is resolved. The position of the tracheostomy tube, through a small hole in the neck, is thought to be more comfortable for patients, easier to keep secure, and thus enabling health care workers to mobilise patients, perhaps sitting them out in a chair as their individual condition allows (Rana et al., 2005). In a systematic review and meta-analysis of five randomized control trials, Griffiths et al. (2005) identified that where patients had a tracheostomy within the first seven days of being mechanically ventilated, this resulted in a shorter length of time ventilated and, consequently, a reduced length of time in intensive care. Recently, however, further trials have challenged these findings (Tracman, 2008), suggesting that the earlier insertion of a tracheostomy, in critically ill patients, does not always improve outcomes.

The lived experience of critical care patients with a tracheostomy was explored by Sherlock et al. (2009) using a phenomenological approach. A total of eight participants were interviewed in order to explore the experience of patients with a temporary tracheostomy inserted while in hospital and also to evaluate the adequacy of information provided for patients. The findings revealed that all participants acknowledged that suction of the tracheostomy tube, to remove secretions, was important and beneficial. However, in addition all participants experienced discomfort or pain and dreaded the suction procedure. Participants experienced

difficulty in swallowing and eating, and some experienced anxiety, fear and panic when it was time for the tube to be removed. While this study was intended to focus on the adequacy of information, participants had little to say about the information they needed; rather, they wished to talk about suction, swallowing, fear and discomfort. This study demonstrates the importance of qualitative studies in eliciting unanticipated findings and the importance of taking patients' experiences seriously even though Sherlock et al.'s (2009) study goals were not met. This lesson was an important one for my own study.

Donnelly (2006) in a qualitative study investigated the experience of having a tracheostomy tube changed. In this study 4 participants were interviewed using an unstructured approach. The findings indicated that, for participants, the process of tracheostomy changing was far more than a technical process. The participants said that they needed to prepare themselves psychologically, as they had to be able to trust the individual members of staff involved and also feel confident that they were competent to carry out such a procedure. This study is valuable as it contributes a new dimension to a technical process. In my experience the mechanical process is usually explained to a patient in preparation, but this explanation would not necessarily include the above key point. Donnelly's (2006) study is limited due to the very small number of participants nor is it clear who was involved in the data collection. Furthermore, a brief discussion regarding how the procedure was actually undertaken would have been useful in order to determine its relevance in another critical care unit.

There are some products available on the market to enable patients to talk with a tracheostomy tube in place. Most of these products can only be used with well patients who have a permanent tracheostomy in place and do not require the assistance of a ventilator to breathe. Within critical care most of these products are not suitable because the ventilators are intolerant of a speaking valve. One such product, the Passe Muir Valve, is an example of this. It works by allowing, on inspiration, gas to flow from the ventilator down the tracheostomy tube directly into the lungs. However, on expiration, the exhaled gas leaves the body through the pharynx and it is this exhaled flow of gas through the vocal cords that enables the patient to speak (Hess 2005). This issue is relevant to my study's findings as it is to the implications for practice which will also later be considered in the discussion section.

Communication.

When patients require respiratory support from a ventilator, it is necessary to have an endotracheal tube placed in the throat which passes through the vocal cords. As a consequence they are unable to speak. In a descriptive study, involving 29 participants, Patak (2004) explored the frustration experienced by conscious ventilated patients who were unable to communicate. This study employed a structured interview with some open ended and some closed questions. Participants were interviewed within 72 hours of extubation and the length of time ventilated was over a period of 3.5 days, on average. This study also excluded patients with tracheostomies. They found that most patients reported a high level of frustration in

communicating their needs while being mechanically ventilated. Furthermore, there was no correlation between the length of time ventilated and the level of frustration. Moreover, most patients still relied on non verbal forms of communication, for example, mouthing words, gesticulating, nodding or shaking the head or, if able, writing messages. Patients stated that nurses asking the correct closed questions, requiring yes or no answers, helped guide them and relatives through the communication process. They also found that 19 participants thought that healthcare professionals did help them with their communication difficulties. However, the participants were also interviewed on the critical care department, an environment where they may have still felt vulnerable and disempowered and possibly may have felt the need to talk up the value of professionals' communication skills. Nevertheless, Patak's (2004) work does emphasise the potential impact healthcare workers can have in alleviating distress caused by not being able to communicate.

Happ (2000) attempted to investigate the communication between nurses and an older group of patients using participant observation and semi-structured interviews. They found that there were psychologically detrimental effects, including frustration, anger or feeling invisible, if a patient was unable to communicate. The key concept of 'voicelessness', in older critically ill patients, emerged in Happ's (2000) study. The study identified how this state of voicelessness may dictate the type of care patients receive. For example, communication barriers resulted in medical staff not having meaningful discussions with their patients regarding their treatment. 'Voicelessness' also influenced the response of the patient to their condition and the environment. By using participant observation, this study adds a new dimension to this topic, as often the perceptions of both patients and health care workers may differ from factual

events. This point is particularly important for health care workers as they may assume that they communicate well with their patients, when in fact, due to frustration and fatigue, many patients learn to modify their attempts at communication, thus not communicating many of their needs (Happs, 2000). This important study only involved a small sample of 10 participants, which limits its generaliseability. Indeed, Happs, unfortunately, was only able to interview 4 of the participants because of the co-morbidities experienced by participants. It was also not clear how long participants were in intensive care or hospital. However, the concept of ‘voicelessness’ is, as will become clear, important within the study reported here.

Alasad (2004) attempted to explore the experiences of critical care nurses regarding verbal communication with critically ill patients. This was a qualitative study with 28 nurses and 240 hours of observation in intensive care. Alasad (2004) found that nurses spoke about the importance of good communication within good nursing practice. The evidence demonstrated that communication was not effective but interpreted as a barrier, for nurses, to getting tasks completed. This finding fits with my own professional observations. Additionally, it was found that sedated patients received minimal communication from nurses and that the nurses preferred to care for sedated patients as they were less demanding. Overall, the level of communication was determined by the level of responsiveness of the patient. The study does not indicate how the sample of nurses was recruited nor does it indicate the characteristics of the critically ill patients they cared for. However, the most important conceptual problem with Alasad’s (2004) work is that the term good communication is ambiguous. Perhaps a better term would be effective communication, where nurse and patient have understood each other, and both parties are able to acknowledge this.

Alasad's (2004) Jordanian study findings confirm those from an older English study by Ashworth (1981), who interviewed patients within sixteen days of leaving intensive care. Ashworth also found that patients' did not feel treated as though they were individuals and time was not planned into the care provided for meaningful communication. In Alasad's (2004) study the amount of time for a nurse-patient interaction was documented, and many interactions were found to last less than one minute.

Leathart (1994) also explored nurse - patient communication and found the duration of interaction to be less than thirty seconds, and at most two minutes, within critical care environments. Leathart (1994) found that communication patterns, by critical care nurses, to be a learned behaviour developed through protective mechanisms that insulate the nurse from anxiety and stress. Such defence mechanisms are often demonstrated through depersonalisation of the patient and through ritualistic care, which undermines ideas and practices about individualised compassionate care. Joblanski (1994) also found, as did Patak (2004), that healthcare providers, especially nurses, are the communication gatekeepers and ultimately control the type of experience that mechanically ventilated patients have within intensive care.

Sleep Disturbances

Linderman and McAthie (1999) define sleep as a period of diminished responsiveness to external stimuli that regularly alternates with periods of wakefulness. Sleep involves two phases: (i) active sleep, commonly known as rapid eye movement (REM) sleep, (ii) quiet sleep, called non-rapid eye movement (NREM) or deep sleep (Williamson 2002). The function of REM sleep is important for cognitive restoration

and may affect memory storage. REM sleep is very important to critically ill patients, as often they have received continuous sedatives and will have experienced altered sleep patterns. Sleep deprivation is a common experience for patients in critical care. This is where the amount, quality and consistency of sleep is reduced (Honkus 2003).

There are many factors which contribute to sleep deprivation for critically ill patients, for example environment, noise, illness, pain, and the need for 24 hour nursing care. Indeed studies have demonstrated a strong causal relationship between a noisy critical care environment and a marked reduction in REM sleep (Topf et al. 1993). In 1999 The World Health Organization (WHO, 1999) issued guidelines regarding acceptable dB (A) levels of noise within hospitals and specifically recommended further attention and research be focused in critical care environments on the noise levels experienced by neonates inside incubators. Some noise within a critical care environment can be attributed to alarms from various pieces of equipment sounding at regular intervals. Baker (1993) identified that alarms on some equipment, used in critical care environments, reached 70 dB(A) and was akin to close heavy traffic. Other noise can be attributed to people's voices, telephones, cleaning equipment, and general nursing or medical interventions (Fontaine et al., 2001).

In order for patients to tolerate a variety of treatments there are some drugs, commonly used in critical care, to promote sleep or unconsciousness. However, such drugs can have undesirable effects. For example Benzodiazepines can compound sleep disturbances and other sedative-hypnotics and analgesia can reduce sleep, resulting in a lighter sleep (Dines-Kalinowski 2002). A potential further reason for

sleep disturbance in the critically ill patient is the need for 24 hour nursing observation and nursing care. Initially, when patients are admitted to critical care many of them require continuous minute by minute monitoring due to the instability of their illness. However, as their condition improves, and sedation is discontinued, repetitive regular monitoring may not be necessary.

Tamburri (2004) undertook a retrospective quantitative study, with 50 patients, analysing patients' charts to establish the frequency or type of care interaction by nurses within four intensive care units. They found that the frequent and repetitive nature of care left little opportunity for patients to sleep. Only 6% of patients were left undisturbed for a period of three hours during any 12 hour period in this study which focussed specifically on night time. The limitations of this study include that sleep could not be measured, sedation is not considered although it may be relevant but most importantly this study does not examine the patients' experiences.

Additional observation and interview components may have improved this study, but the scope of the problem for patients is at least confirmed here. Celik (2003) in another retrospective study produced similar findings to Tamburri (2004).

There are many reasons, outlined above, that may contribute to critically ill patients experiencing sleep deprivation. Gabor et al. (2003) investigated the specific problem of noise and its impact on sleep by studying two participant groups. One was a group of six healthy people sleeping in an intensive care unit over a twenty four hour period, and the second group comprised seven ventilated critically ill patients. Using polysomnography the study found the patient group experienced fragmented sleep, with very little deep and REM sleep, compared with the healthy participants and this

was in spite of noise being a variable for both groups. Furthermore, only 30% of arousals or awakenings in the patient group were noise or patient care related.

Cooper et al. (2000) also used polysomnography to investigate brainwaves, heart rate, body movements and breathing during sleep, and found that mechanically ventilated patients have changes in sleep patterns which are usually the characteristic of acute illness. Such technical studies are valuable because they aid understanding of the fragmented sleep experienced by intensive care patients, but do not provide insight into the complexity and dynamism of individual patient experiences in a holistic sense.

Finally, there is evidence that nurses' assumptions about how well a patient has slept may be incorrect. In a study by Richardson (2007) a comparison was made of sleep assessment tools used by both nurses and patients within intensive care. They compared nurses' and patients' assessment of sleep using three different types of sleep assessment tool to establish how well patients' slept. Richardson found a high degree of error by nurses when assessing patient's sleep, despite their providing one to one contact with patients when providing nursing care in a critical care unit. This study did not measure sleep objectively, it only investigated nocturnal sleep and did not assess the experience or training of the nurse participants. Nevertheless, Richardson (2007) concluded that nurses should assess patients sleep more accurately by simply asking the patient about their experiences.

Summary.

Evidence within the literature review indicates that issues of power and control are central to understanding patients' experiences within a medicalised, technical intensive care context. Issues of power and control are linked to ongoing problems like sleep disturbances, and the disturbing effects of dreams and unreal experiences experienced by patients within critical care. Such problems are also compounded by patients being dependent, when breathing using a tracheostomy tube, with the consequent and associated experience of serious barriers to communication leading, in turn, to voicelessness. Indeed, such difficulties for patients are reinforced, evidence suggests, by threats to their privacy and personal dignity in critical care. Nevertheless, the literature also confirms the particular importance of family members as providing social support and a sense of security for these vulnerable patients.

Some of the methods used in the literature examined above are relevant to exploration of the experiences of conscious patients attached to a mechanical ventilator as is reported within this dissertation. Qualitative approaches with participants were found to be most useful in gaining access to patients' experiences (Whalin, 2006, Engstrom & Soderberg, 2007, Hupcey, 2001, Granberg, 1997, Rundshagen, 2001). However, following this review of the literature it is clear that many studies do not address the experience of patients who may spend an extended period of time in intensive care. Studies include a large proportion of participants whose length of stay, in intensive care, was 7 days or less (Engstrom & Soderberg, 2007, Patak, 2004, Roberts & Chaboyer, 2004, Granberg, 1997, Rundshagen, 2001). Furthermore, the time lapse between discharge from an intensive care unit and the commencing of data collection was sometimes greater than six months, in some studies. The experiences of patients who are conscious and ventilated in an intensive care environment for an extended

period of time are neglected within the literature. Indeed within critical care the needs of the critically ill, who require *prolonged* periods of ventilation, are at risk of being overlooked, and it is the experiences of this group of patients that this qualitative study has addressed. The literature review identified that there is little evidence applied to the planning and implementation of nursing care for such patients in critical care. The following aims and objectives are intended to therefore address these deficits within the evidence.

3. Aim and objectives.

Informed by the author's professional experience of nursing patients within critical care and underpinned by analysis of the literature, the following aim and objectives guided the study.

Study aim:

- Exploration of the experiences of intensive care patients while being attached to a mechanical ventilator and in a conscious state, in order to identify implications for nursing practice, policy and future research.

Objectives:

- Complete a critical review of the literature regarding intensive care patients' experience of being attached to a ventilator while in a conscious state.
- Gather and analyse rich, in depth data about patient's experiences using semi-structured interviews within a rigorous qualitative approach.
- Identify and discuss implications for dissemination of findings, nursing practice, policy and the development of a new wider study to build on this dissertation's findings.

4. Methodology and methods.

Qualitative methodology.

To address the research aims and objectives, to promote trust and emotional safety for participants within individual interviews, and to successfully gain access to personal accounts about their experiences qualitative methods were employed within this study (Bowling, 2009). This qualitative approach was particularly appropriate as it was intended to enable participants to talk about their experiences, in their own terms, and provide insight into the aspects of the participants' experiences for which there is currently little evidence. Qualitative research is different to traditional quantitative methods in that it does not attempt to manipulate the environment but is naturalistic in that it attempts to study people in natural, everyday settings (Bowling, 2009, Silverman, 2010).

Qualitative research does not attempt to explore and analyse people's experiences by using measurement or numbers, but explores people's meanings and experiences in their own terms and the data produced is often in the form of text (Silverman, 2010), in this case text derived from recorded semi-structured, face to face interviews undertaken within individual patients. The advantages of these methods include being able to access in-depth rich data about participants' complex and dynamic life experiences in highly detailed accounts, which is particularly valuable if little has been written about such experiences before (Bowling, 2009). This approach is interpretative in that it attempts to employ a 'bottom up' approach to research where participants' views, experiences and meanings are central to analysis (Silverman,

2010) as will be clearer when qualitative data analysis is discussed later in this chapter. Qualitative research can also underpin quantitative research in that it provides the early rich data to inform larger studies, as is planned for this study (see further information within the discussion section of this dissertation).

Semi-structured interviews.

Within this study it was decided to *not* employ an unstructured qualitative interview, where there may be few or no questions planned in advance, but to use a semi-structured qualitative interview format that allowed the researcher to guide the interview with flexible use of prompts, where appropriate, that were open rather than closed (Bowling, 2010). The semi-structured interviews within this study were guided to focus specifically upon participants' experiences of being in conscious state while attached to a ventilator within an intensive care unit. This particular design ensured that participants were able to talk about their experiences in their own way and that their experiences were valued and reported authentically. At the same time, this design allowed the researcher to guide the interviews in order to address study goals with an ultimate objective of gaining insight into issues that were relevant to improving nursing practice in the future. The series of open-ended prompts developed to guide the interview process (see appendix one) were informed by the literature review, ethical scrutiny and academic supervision. However, not all prompts were employed but were used flexibly to help the novice researcher think about, and link, both study aims and objectives, on the one hand, and participants' in depth stories, on the other hand, within the interview process. For example, the first phase generative question asked the participants a broad open question about their

time within intensive care as way of enabling them to speak about their experiences, in their own terms, before the interviewer focussed on the more specific prompts developed for phase two. The second phase questions, not all of which were used, were identified to enable participants to talk about particular aspects of their experience which the first generative question may not have elicited. In fact, the first generative question was most useful in generating a valuable in depth interview with all participants.

The role of the researcher within semi-structured interviews.

The position of the interviewer and potential influence of the interviewer within qualitative research is now recognised as being open to consideration, understanding and analysis. Holstein & Gubrium (2004) have argued that the interaction between interviewer and participant is an active process, one where the position of the interviewer and participant is acknowledged. Indeed, it is the interaction between two people that contributes to the construction of knowledge within fieldwork. Issues of power and empowerment are important to this study, and my medical power as an experienced intensive care nurse, manager and researcher is important in this respect and will be further analysed within the limitations sub-section of the discussion.

However, it is worth noting here that it was anticipated that the researcher's knowledge, of the phenomenon under study, as a nurse, albeit from a different perspective from that of the participants, could assist the description and interpretation of the phenomenon being researched.

This style of interviewing was also chosen because it offers flexibility, allowing the researcher to probe further on specific topics and specific participant concerns as they arose. Pope and May (2000) discuss the merits of this flexible style of research design describing the benefits of commencing the analytical process early, including while still collecting data. For example, after the first interview the unanticipated importance of disturbing vivid dreams for participants became clear. This method of research enables the qualitative researcher to explore new territories and redefine questions and pursue new emerging themes as they arose. The study did generate findings that both answered research questions but also provided important unanticipated findings.

Method.

In keeping with the chosen methodology, the method of data collection took the form of a recorded, semi structured interview with each participant. Each interview varied in length between 45 and 60 minutes, with a limit of 60 minutes established by the researcher, in advance, in order to prevent tiring the participants. The interviews were conducted with participants who had been cared for within an intensive care unit, and took place on hospital wards where they were recovering and rehabilitating before being discharged home from hospital. The rationale for this was to gain access to experiences that may be still fresh in their minds, and also to ensure that experienced clinical staff would also be available support the patient should participant concerns related to the interview arise later. Within the trust the intensive care department have a 'follow up' service to provide counselling support for patients as they leave the hospital which was also intended to be used if necessary. No specific concerns were

raised by participants but this anticipatory plan was necessary to deal with any potential issues that may arise.

Purposive sampling.

The sample chosen for this study was purposive (Carter & Henderson 2005), as this allowed identification of people who have experienced the phenomenon, could communicate their experiences first hand to the researcher and allow research objectives to be met. Purposive sampling was necessary to enable the exploration of the experience of being a long term patient on the intensive care unit. It was intended that 6 patients would be interviewed about their experience of being a patient in an intensive care unit which was achieved. The participants were recruited from a group of patients discharged from the same intensive care unit. There were five men and one woman. Two other women agreed to participate in the research study, but were discharged home earlier than planned, and so were unable to be interviewed. The participants ages ranged from 33 to 71 years, all were white British from working class backgrounds. All participants spoke English as a first language. Unfortunately, no middle class participants or participants from ethnic minority backgrounds were recruited, simply because such potential participants were not available at the time of the study. Further research is needed in the future to interrogate the differences in the experiences of participants undergoing similar experiences but with specific reference to nationality, gender, ethnicity and social class.

Criteria for selection of participants.

Inclusion criteria included patients' first admission to an intensive care unit, a length of stay in intensive care greater than two weeks, that they had a tracheostomy as part of treatment, that the tracheostomy was no longer in place and that they had full mental capacity. Participants who were experiencing a first admission to an intensive care unit were chosen because it was speculated that participants who had experienced intensive care previously may confuse the different experiences. Participants' length of stay on the intensive care unit was a minimum of two weeks, this was to ensure for participants, the acute phase of their critical illness had subsided, and they would have spent some time conscious, awake, attached to a ventilator and aware of their environment.

Often patients who spend a protracted length of time within intensive care do so because of the difficulties in weaning them off the ventilator, often with chronic multiple health problems. In fact, the participants' length of stay in critical care was a minimum of 21 days and a maximum of 61 days. Indeed, three of the participants were in critical care for longer than 50 days. These protracted periods of time in intensive care are important to note as this new study was attempting to overcome the limitations of previous qualitative studies, discussed in the background section, which recruited patients having spent shorter periods of time within intensive care.

At the time of the interviews, participants were situated on general hospital wards and their health was improving. Finally, all participants no longer had a tracheostomy tube inserted at the time of the interviews, but all had had a tracheostomy tube

inserted as an earlier part of their care when they were critically ill in the intensive care unit.

Selection Process.

Once a patient had left the critical care area and was being nursed in a ward area they were visited by the critical care outreach nursing team on a daily basis. The members of the critical care outreach team were briefed about the criteria for this research project. Providing the patient was continuing to make a good recovery, the outreach team approached suitable potential participants, to ask their permission to pass on contact details to the researcher. The researcher then provided an introductory letter (Appendix two) and a patient information sheet (Appendix Three) to the potential participants. In the event that a potential participant was unable to read or had visual problems, the researcher would have negotiated with them a method which may suit their needs better. In the event this was unnecessary.

Ethical considerations.

Beauchamp and Childress' (1989) four ethical principles were employed to frame the ethical approach to this study. These four ethical principles are respect for autonomy, beneficence, non-maleficence and justice. Respect for autonomy concerns, for example, the rights of patients to information about the project, their right to withdraw at any time, and their right to be provided with verbal and written informed consent. Beneficence involved, for example, responsibility to treat participants in a respectful, courteous and caring fashion, but also to ensure

anonymity was maintained. Non-maleficence involved doing no harm: no participants were harmed by this study. The principle of justice involved being fair and equitable. In this respect it was particularly important, in working with participants who were less powerful than the researcher to employ a qualitative approach to allow them to talk about their experiences in their own terms.

Specific ethical considerations addressed within the study also included provision of a clear plan for participants, within the participant information sheet (Appendix three). A clear plan was presented as an example of what will be required of them as participants. The participant information sheet also stated that confidentiality and anonymity will be maintained, the data will not be seen by anyone in the Heart of England NHS Trust in its raw form, and participants' identity will not be disclosed to anyone else. However, the document also stated that confidentiality will not be maintained should malpractice, by health professionals, be identified during the course of data collection, as the researcher is bound by the NMC Professional Code of Conduct (NMC, 2008). For example, should a patient claim they have been mistreated in any way, the researcher would be duty bound by the professional code of conduct to report it. Fortunately, such an eventuality did not occur.

The taped recordings of the interviews, prior to typing, were stored in a locked draw within a locked room. Following transcription by the researcher the tapes were destroyed. My employing Trust policy indicates that data can be archived for 10 years. However, while data has been kept on a password protected computer all data will be destroyed once the study is completed. Data in its raw form, before and following transcription, was stored within the Critical Care Outreach Research

Department on the Heart of England Foundation NHS Trust site. The data was only used for this specific research project. If the participant was no longer comfortable with the process at any stage they had the right to withdraw. In the event of this happening arrangements were made for them discuss any issues either with the researcher or someone else within the Trust, for example the Patient and Advisory Liaison Service, the Research and Development Department or the Critical Care Outreach Team. Fortunately, this eventuality did not occur. Interviews were conducted in private, in rooms where confidentiality could be maintained, and free from interruptions.

Written informed consent was gained from each participant. In order to identify suitable participants the researcher liaised with the Critical Care Outreach nursing staff whose role was to visit patients recently discharged from ICU to the ward environment. The researcher approached potential participants, providing an information sheet and answering any questions the participant may have had. The patient then had at least forty-eight hours to consider whether or not they wished to participate in the study, before formal written consent was obtained.

The study proposal was presented to Coventry University research ethics committee, an NHS Local Research Ethics Committee and the Heart of England NHS Trust research and development committee for scrutiny and a favourable ethical approval. The role of the Trust research and development department was to ensure that the researcher was safe and competent and to ensure all ethics approval requirements are in place. The NHS indemnity insurance was also provided by my employing Trust.

Only people who spoke English as a first language were included in the study. However the decision to do this was not simply one of convenience, as data collection took the form of the researcher interviewing all the participants and transcribing the scripts herself. The translation of transcripts would have negated the collection of reliable and culturally sensitive data and thus undermined the basic aim of the project.

Qualitative data analysis.

The analysis followed an inductive thematic approach (Silverman, 2010) to guide the researcher at this crucial stage of the qualitative research process. This process of thematic analysis was informed by reading of the literature, analytical notes undertaken during the fieldwork period and auditing of analytical decisions by the university academic supervisor. All interviews were transcribed verbatim, and read in sequence a number of times in order to explore the true essence of the content of each interview. This repeated reading helped understanding of data and informed the identification of codes to enable the categorisation of data. Within qualitative analysis, the process of induction ensures that the data is condensed and emphasis is placed on preserving the essence of participants' experiences (Flick, 2006).

Illustrative quotations are used to present results, in the findings section, in a way that allows identification of themes (or patterns) within the data, but also allows identification of diversity and outliers or deviant cases (Silverman, 2010). Some categories were influenced by the interview questions, for example the frustration

associated with communication using a tracheostomy tube, was an anticipated finding. However, the coding of the material grouped under the categories remained data driven and, therefore, this allowed the participants' perspective to shape the analysis structure (Edwards & Talbot 1999). For example, the disturbing and the life like nature of dreams was not anticipated fully within the original proposal, nor elicited by specific prompts, but emerged during the interview process.

Study trustworthiness.

In order to ensure that this qualitative study was robust it was vital that it must be rigorous. The concept of trustworthiness, as identified by Lincoln and Guba (1985), incorporates four principles of rigour within qualitative research which are: confirmability, dependability, transferability, and credibility. The trustworthiness of this research study has been achieved by adherence to those principles.

Confirmability.

Confirmability involves demonstrating that the research is conceptually and methodologically coherent and the process follows a logical sequence. The findings from this research will be reviewed within the broader context of existing research regarding the patient experience in intensive care in the discussion section. No research process is perfect, and every study has limitations (see discussion section), but this study was rigorous and coherent shaped by evidence and close guidance from my academic supervisors.

Dependability.

In order to ensure consistency of data and enhance internal validity, all interviews were conducted by the same researcher within a similar time frame. An audit trail was evident throughout the study and supervisors also analysed data independent of the researcher to scrutinise the analysis decision making process. Furthermore, the researcher's field notes regarding the interview process were used as a source of data, and will inform the discussion section of this dissertation. The choice of method and research design were appropriate in order to address the research questions, and interpretation of data was not biased (Polit & Hungler, 2001).

Transferability.

In order to demonstrate external validity and the potential transferability of findings to other situations, the use of purposive sampling was intended to ensure that the participants selected were representative of the target population. The use of 'thick' in depth, descriptive data, regarding the participants and their experiences, alongside the application and integration of the researcher's observations enhanced the transferability of this study. However, it should be recognised that transferability is limited to the specific intensive care setting not least because of the small sample size, more men than women were recruited and there were no ethnic minority participants. While this study was primarily intended to help develop practice within my intensive care department, plans for a future wider study are considered within the discussion section of this dissertation.

Credibility.

Credibility refers to the success of the study in authentically describing and analysing patients' experiences. In order to reduce the risk of bias, the researcher, through a process of reflexivity made methodological reflective notes, which allowed consideration of positionality during the interview process and when analysing the data. It is also worth emphasising that saturation was achieved in this study: this is the process of collecting data to the point where new data does not yield new information relevant to the study aims and objectives (Polit and Hungler, 2001).

Management of study.

The researcher was responsible, as a student, for undertaking this study, but was guided and supervised by two experienced researchers and academics within the University of Coventry. Ethical scrutiny and three favourable ethical opinions took many months to achieve between December 2007 and March 2008. The fieldwork was undertaken between March 2008 and November 2008. Data analysis began in March 2008, but the bulk of the analysis took place between November 2008 and March 2009 within the writing up process.

Summary.

This exploratory qualitative study, to investigate the experience of patients, nursed within a critical care environment, when conscious and connected to a mechanical

ventilator, was undertaken with 6 participants, who were recruited using purposive sampling. The findings of the process of qualitative data analysis are now considered in depth in the next section of this dissertation.

* All participants' family contacts have been given pseudonyms to preserve confidentiality.

5. Study findings.

This section of the dissertation will present the findings of the study, in a series of interdependent themes. Thematic analysis was used to identify themes within the data but also outliers where some participants' views are at odds with a theme (Silverman, 2000). The six interdependent themes are:

- **The centrality of family visitors' presence and social support within patients' critical care experiences.**
- **Losing your voice: unresolved communication difficulties.**
- **Difficult thoughts and feelings associated with physical, personal care by health professionals.**
- **Asleep or awake? Vivid, violent, confusing and disturbing dreams.**
- **A noisy and disorientating environment.**
- **Vulnerability and loss of control over body, mind and identity.**

Although the above themes are interdependent they will be presented in turn, but the links between themes clarified within the following discussion.

Theme One.

The centrality of family visitors' presence and social support within patients' critical care experiences.

All participants saw visiting as a vital component in the day of an intensive care patient. In fact, for some the whole day revolved around visiting time. The data demonstrates that visitors play a key role in many aspects of a patient's recovery. This theme has two key elements: the first is the role of family and friends from a patient perspective. Secondly, this theme will also report how vital family and friends were in enabling patients to '*carry on*' and not to '*give up*'. Two of the participants in this research study had their partner present, at the bedside, for approximately 10-12 hours per day while in critical care. This is unusual, from the researchers' practice knowledge, and an arrangement each participant's partner had to negotiate with nursing staff.

Generally there are two slots in the day allocated as visiting time: 12pm – 3pm and 5-9pm, a total of 7 hours per day. When participants were asked about what was the best part of the day, or which aspect of the daily routine they liked, all respondents said the same thing: '*visiting time!*' For example, one participant said:

“ Visiting was absolutely necessary. I couldn't have done it without Meg, no way... I think you see some old people and I've heard like how people don't come up and see their relations and stuff.... I could understand how they would give up pretty quickly. Because to go through that experience by yourself without being reassured and

without being told what was happening. The support you need is massive.” (Patient ID 3).

In this excerpt the participant is emphasising that the support needed was ‘*absolutely*’ necessary to avoid ‘*giving up*’ on life, which it was anticipated would happen without the support of the family. Such support included being informed about the activities around them and things happening to them.

It is worth noting that all but one of the participants had a partner. Participant ID 1’s partner had died 7 years ago. Although he had two adult sons, who visited daily, he was the only one who referred to the nursing staff as a source of encouragement: “*they would jeer me on*” a term that locally seems to mean to encourage someone. Participant ID 6 described how he remembered his daughter holding his hand and talking to him, willing him to ‘*come round*’.

All the participants relied on their families or visitors for a link with the outside world: a link with the participants’ home life and, for some, recognition of their identity in a confusing and disorientating environment. Close family members and friends were the key people in helping understanding, interpreting and explaining what had happened to them in the past, for example: regarding their illness or operation or the accident or other reasons for being in critical care. They were also key to understanding what was happening to the participants in critical care on an ongoing basis. Participants relied on family members and friends to try and make sense of their experiences. Participant ID 3 discussed how he only trusted what his partner told him. If she said it was so then it must be right or acceptable, from his

point of view. These issues, as will become clear, are linked to the findings regarding the complete loss of control and vulnerability that participants experienced (Theme 6).

For some participants, family members played key roles as a patient advocate. For them, the only person who could communicate, speak up, or explain their concerns on their behalf was the family member. As previously mentioned, two participants had their partners in attendance for many hours a day. Both of these participants talked about how they relied on their relatives for information about what was happening, and, if some new procedure or treatment or activity was to be introduced, they helped them know how and when that would take place. For example, participant ID3 said:

My sister came to visit me and when she saw the state I were in, she said to the doctor: 'You had better put him on a life support machine'. The doctors had a little chat and said: 'They didn't think it would do any good but we will give him a tracheostomy'... And that's what they did. ...It was only my sister complaining, she said: 'He's dying, he can't breath'. I don't actually remember... it's what my sister told me" (Patient ID3).

For this participant, in his view it was his sister who had advocated the use of a ventilator to medical staff, who had recognised he was close to death, had understood that he was struggling to breathe and had told the doctors what they needed to do. Participants also described how they felt responsible for their visitors. For example, participant ID 2 remembered an occasion when some friends visited, in the early stages of her illness, and that she felt that she had made them quite distressed:

I could see tears in their eyes when they saw me on the machine. I thought it's not fair on them, bringing them into the environment of ITU, it's a scary place. (Patient ID 2).

For this participant the fearful nature of the ITU, 'a scary place', and its range of technology was considered to influence the psychological wellbeing of their visitors, for which she felt responsible. One participant (ID 4) talked about how he had thought that it would have been better, for his wife, if he had died in order that she did not witness and be involved in his critical care experience:

I thought my missus would have been better off without me. If I had died, I'd have been dead and cremated by now, and she would be trying to pick herself up." (Patient ID 4).

Participants also talked about being close to death, and, in some cases during the earlier stages of their illness, may have thought that they wanted to die because of the difficult situation they were in and how they felt at the time. Patient ID 4 explained how he wished he had died and that he might be better off dead, rather than face an unknown future with the possibility of spending the rest of his life in bed. However, in contrast, all participants said that it was their families that gave them the will to continue. For example, participant ID 4 talked about his experience, when he was first admitted into the accident and emergency department at the hospital. He was very ill and subsequently quickly taken to theatre for surgery. He said:

The only thing I remember was Connie shouting: ‘You promised you would never leave me; you promised you would never leave me’. That is what I remember! (Patient ID 4).

For this participant this plea was important, helping him with the determination to psychologically ‘carry on’ or ‘fight it’ as he later put it, a pattern recurring in the stories of all participants when they talked about daily visits. Participant ID 2 described wanting to die, then seeing photographs of her husband and children and subsequently making a conscious decision that she was not ready to die yet and being determined to ‘fight back’. Participant ID 3 discussed the importance of seeing a familiar face and believing that if he was to survive the experience of being ill in intensive care, he could and would go back to his life as it was before. Indeed, this participant reported that his heart had stopped three times, and on one such occasion he remembered it vividly. He talked about a nurse being present at the bedside talking to a group of student nurses when this disturbing event happened:

...and I was looking at her you know, and then I thought I’m going here, I just knew I was going. I just looked at her and I went down, and I was out. When I came round they were all pumping my chest and saying my heart had stoppedI just felt I was at the end. I didn’t feel any pain or nothing; I just knew I was going to nothing. ...I can remember people pushing my chest down when I was coming round and then them saying: ‘Blimey you gave us a fright’ (Patient ID 3).

According to this participant, the nurse present at the time of this event, later told him that she was looking at him and he gave her such a smile before he had a cardiac

arrest. This participant later had a permanent pacemaker fitted, in order to prevent further slowing down of the heart rate or the heart stopping completely. However, one of the key problems for participants was that they could not always communicate well with their visitors because the latter could rarely lip read, creating communication difficulties:

... I mean if they [visitors] are here for an hour, er you know it's a long time to try and get things across. (Participant ID 1).

The centrality of visitors' regular presence within critical care was perceived to be essential in order to provide a range of differing kinds of social support. That support was sometimes jeopardised by practical communication difficulties, as the last excerpt emphasises. Hence, visitors' presence and support is mediated by limitations of the processes of communication, which will be addressed now.

Theme Two.

Losing your voice: unresolved communication difficulties.

The experience of not being able to talk was distressing for all but one of the participants. Not being able to use their vocal cords had an immense effect on their sense of disempowerment. Indeed, not being able to make themselves heard was associated with an enormous sense of frustration, which in some cases led to anger. However, there was no way of expressing anger, or fear, or pain which resulted in a sense of isolation:

The whole experience for me was really frustrating. I became angry inside but I had to learn to deal with that pretty quickly, because I had now way of expressing myself so it was a waste of time...there was no way of me getting anything across to the nurse. I think at that stage I was more or less a vegetable, I couldn't do anything at all. (Participant ID 3).

The frustration and anger, associated with communication problems, for this man leads him to consider himself a 'vegetable' a pejorative and disturbing way to talk about oneself. Similarly, participant ID 3 talked about medical staff ward rounds, indicating that he could hear everything that was being said, but, at the same time, was unable to correct what he considered to be inaccurate information regarding him and he was also unable make a contribution to the 'round'. All participants discussed witnessing the doctors' ward rounds and gaining little information from this experience. One participant described how doctors talked amongst themselves and another described how they 'stand at the bottom of the bed in a huddle' (ID 2.). Participants ID 3 and 4 talked about how they would try and listen but often did so in vain. During the interviews the researcher explained to the participants that each day a medical plan of care was made for each patient, but none of the participants indicated that they were aware of such a plan. In contrast, one participant (ID 4) emphasised the following point:

They could have explained things. Well it's your body... and all that and if there is something wrong they should say. You would feel better. I know you would probably worry, but when you know nothing you worry more. (Patient ID 4).

For this participant, it was his ‘*body*’ but was not told enough. He knew he would worry if some disturbing information was provided but without that information he may feel worse. However, some doctors were remembered, for, on occasions, giving what participants considered to be important information. For example, participant ID 4 discussed how a surgeon came to see him to explain what had happened during the operation, that the participant now had a stoma and how the surgeon had not expected him to survive in theatre. Participant ID 2 said she felt reassured by a doctor talking at length about having her tracheostomy removed. She also experienced a real boost in confidence when a consultant came to see her and exclaimed ‘*bloody marvellous!*’ when he observed how well she was doing.

All the participants said that having no voice was frightening as they were unable to attract anybody’s attention when needed. For example:

If nurses were helping others and you wanted to attract attention you can’twhen the pipe gets disconnected, [tubing from the ventilator to the patient] well you panic... you are still breathing so you are alright. But you know when the nurses are not close at hand, you try and put it back together yourself...but you’re all over the shop. You need a panic button... (Participant ID 1).

The lack of a voice, the limits to communication, the loss of control, the equipment problems and the varied presence of nurses was linked, for this man, with panic and being ‘*all over the shop*’. Some of the participants also described methods for trying to attract attention of nursing staff, including waving and removing the oxygen saturation probe from fingers as this would cause the monitor to ‘*bleep*’. Another

patient used to bang a beaker of juice on the bedside table to attract attention, especially if the breathing tubing had come disconnected. Tapping or banging the side of the bed with a pen was another method used. All the above methods were effective to some degree, but none of these methods were initiated by nursing staff as agreed methods of communication. They were all devised by individual patients as a means of attracting the nursing staff's attention when they needed something.

For patients, attracting attention was only the first stage in an effort to making themselves heard. Once they had the attention of someone they then had to make themselves understood. Two participants discussed how they were unable to move their heads or limbs and so had to rely on blinking or closing eyes, while another said he was able to wiggle toes. These methods also relied on the healthcare worker, or visitor, asking the right closed questions and a lot of guesswork to establish even limited communication. Participants who were more able could attempt to write messages but this was not an easy task:

My handwriting was rubbish because you feel so weak and hazy.... Also the oxygen saturation probe on my finger stopped me writing messages. (Participant ID 1)

All participants relied on others lip reading, but found this immensely frustrating and none of the participants thought that nursing staff were good at lip reading. For example:

It was very frustrating... you have got to keep repeating yourself. Nobody knows what you are on about. You're saying something and they think you are saying something else (Participant ID 5).

On occasions, the frustration associated with lip reading experienced by participants resulted in them not bothering to try and communicate. However, one of the participants (ID 1) did think that while the nursing staff were not good at lip reading they were good at anticipating what he may need. Another participant described how he did not really understand why he could not talk and was concerned that his family may think that he did not want them at the bedside. His young nephew later helped by lending him his scrabble board so he could use the letters to make words in order to communicate (ID 6).

Current practice within intensive care units is that nurses '*hand over*', which means they convey information about patients from one staff group to another, as shifts change. Sometimes this '*hand over*' constitutes a walk around the unit, visiting all the patients by a team of nursing staff:

You see like of a morning they would come round and say like this is Josh, he is in for such and such. There would probably be 10–15 nurses would visit everybody.
(Participant ID 5)

When I asked if any of the nursing staff spoke to this participant during these encounters, participant ID 5's response was as follows:

No they would just look as if to say well he's got so and so. I think they were a bit reluctant, because the ward I was in there was one or two dying really all the time. (Participant ID 5).

Participants did not remember the nursing staff explaining to them what their individual plan of care was for the day, following the doctors' 'rounds'. However, participants were aware that nurses did answer many of the doctors' questions regarding the patient. One participant, who had been severely incapacitated, spoke positively of how the nursing staff would spend time talking to him, even if they did not know whether he could understand or not. What was also valued was when nursing staff talked to him about their own everyday life activities, for example:

One nurse would get in front of my face and tell me things about when she went home and had her tea. It was really nice of her to do that. (Participant ID 3).

The above excerpt demonstrates many important components of what constitutes effective communication, including recognition by the nurse of the importance of eye contact and the effort taken in order to achieve it. This excerpt also clarifies that the nurse was giving something of herself and not just explaining instructions regarding a procedure. It is also confirmed, for the participant, that despite his current situation this nurse recognised that his life was once similar to hers and that also saw him as person with an everyday life, a life when he was a patient.

The speaking valve that is used for patients with tracheostomies in intensive care cannot be used when the patient is on the ventilator (breathing machine), as the two

pieces of equipment are not compatible. Therefore the patient with a tracheostomy tube has to be able to breathe unassisted in order to be able to use the speaking valve. This requires the patient's condition to be considerably improved before the valve is introduced and, therefore, the valve is inevitably only used towards the end of their treatment within intensive care. From a medical point of view this speaking valve is used as a weaning tool to see how long the patient can stay off the ventilator. If patients achieve 24 hrs or more continuously off the ventilator then they are considered fit enough to leave the intensive care unit and are transferred to the high dependency unit. The fact that the speaking valve enables a patient to speak is secondary to its use as a weaning tool, the latter being, in my experience, a priority for professionals.

Most of the participants really liked the speaking valve. If the patient could only use it for short periods of time, nursing staff did seem to ensure that its use coincided with visiting time:

Then I remember the staff nurse for the first time putting something in my neck which allowed me to talk.... But I could only talk very softly... that was brilliant that was. When that went in it was the first time, for probably four weeks or so that I could actually talk and express myself ...and join in. I was so happy when that went in, 'cos I could talk to Meg. You know... we actually could talk to each other.

(Participant ID 3)

One participant said that the valve made his throat sore, and therefore he only wanted to use it for short periods of time. Another participant discussed how she had a few panic attacks when they used the speaking valve:

The sensation of the speaking valve was just horrible... I felt this crackling in my chest. A strange noise... the air coming through.....I found it really irritating to be honest, I didn't feel the speech was the most important thing at this point....If I never spoke again, I just wanted to breathe normally without been anxious and having a panic attack. When the valve fell off I found I could breathe better and I was happy just having an oxygen mask on my tracheostomy tube. I really didn't like the speaking valve (Participant ID 2)

For this woman the panic, fear, frustration and anxiety of the presence of the speaking valve was disturbing. In a sense, these findings link to other themes in that difficult feelings, loss of control and a disorientating environment are interdependent and also associated with professionals' interventions regarding personal care. Losing one's voice, then, was associated with a sense of disempowerment, isolation, not being included in ward rounds, being spoken about but not to within nursing ward rounds and not being treated as equals within communication. The methods of the communication used such as removing the oxygen saturation probe or banging a pen on the side of the bed were initiated by patients not nursing staff. This was because there seemed to be no clear recognised method of communication by professionals with participants resorting to blinking or wiggling toes.

Theme Three.

Difficult thoughts and feelings associated with physical, personal care by health professionals.

When this research study was first considered the focus was often on finding out about participants' views about weaning and the plans and routines for the patients' day. Furthermore, it was speculated that they would they have organised their day and routine in a different manner or would they like to have been given more choice and control. However, the data does not confirm this. For participants, what was important was how embarrassed they felt about toileting or being bed bathed, for example. (It should be noted that the design of the critical care environment in which the participants were treated did not include a patient toilet).

One participant had a urinary catheter and a colostomy inserted, which meant he did not need to use a toilet. However, the other five participants found using the facilities for elimination distressing. There were many reasons for this. Emotionally, some participants were embarrassed and participant ID 2 spoke about how degraded she felt recalling, on one occasion, trying to get out of bed herself one night to try and '*clear it up*'. Another participant (ID 1) explained that he was a proud man used to his independence and felt embarrassed or humiliated using bed pans: "*Some people may not care about things like that but I do!*".

Due to the complex treatments, the liquid diet and the types of drug prescribed many patients experience diarrhoea during their time in critical care. This presents problems both for the patient and the nurse caring for them. As one participant (ID 5) said, he would probably have three to four episodes of diarrhoea in the space of one

hour, and this would keep him awake at night. One current nursing practice in order to try and protect the skin around the sacrum area and also to prevent constant bed sheet changes is to apply a bag called a faecal collector to the area in order to drain away the diarrhoea. Participant (ID 5) discussed how he considered this bag to be uncomfortable and unhygienic:

I had a urinary catheter and a bag so I didn't have to get up out of bed. I hated them bags, they were terrible..... Well I used to wake up in the night and you would want to go to the toilet, and all of a sudden you pass more wind or something. It was uncomfortable. I didn't like it... I'd have sooner used a bedpan or a commode. They would change the bag every so often. But it wasn't regular, that bag was on you for 3-4 days. That was not hygienic. (Participant ID 5).

Other participants also found other methods of toileting, for example bedpans, very uncomfortable:

When you're lying flat out with a bedpan it hurts your back, but if you lie at an angle you don't know if you are finished or not. (Participant ID 1).

Participants ID 1 and 2 indicated that the problem of not having a voice was compounded by wanting to go to the toilet, especially when they had diarrhoea. Participants said that when they were fit enough to be able to sit out in chair and use a commode they felt much more comfortable, but indicated that there being only one commode available within the unit was insufficient.

All the participants really valued having a wash in the morning and felt refreshed afterwards. Participant ID 3 would have liked another wash before settling down for the night, and participant ID 2 recounted the day a nurse said that they were going to pamper her which involved washing her hair and putting some make up on. Other participants also mentioned feeling better after having had their hair washed. However, two participants discussed how embarrassed they felt about being washed by a nurse. Associated with this embarrassment was that each day a different nurse may be looking after them which heightened the embarrassment, as this man told me:

“For a bloke at first it’s very embarrassing. One day you have a nurse and then the next day you will have a different nurse and you have to relive it a few times. But then there becomes a point when you’ve got no modesty left anyway and it doesn’t bother you anymore.” (Participant ID 3)

For this man, the embarrassment was linked to a lack of continuity in relationships with nurses leading to dignity being eroded. Participant (ID 2) confirmed this:

“I think the washing thing was better when you were used to a person, rather than having all these different people see you.”(Participant ID2).

Nevertheless, all participants indicated that nursing staff had maintained their privacy and dignity, mainly through the use of screens and curtains when personal care was being provided.

Sleep and rest can be difficult for patients in critical care, as most will have been fully sedated for a number of days which distort individual sleep biorhythms which is problematic when sedation ceases. Each afternoon, as part of the daily routine in intensive care, there is a patient rest period aimed at enabling patients to sleep or rest. Its duration is approximately two hours, and at this time there is intended to be no routine nursing or medical interventions with patients, and no visiting by relatives or friends. All of the participants remembered this time of the day and the lights being switched off, but they also remembered not actually having much sleep. One participant (ID 4) spoke of how often his rest period would be disturbed by both nurses and doctors wanting to do different procedures. Other participants talked about how often there would be something happening elsewhere on the unit and these noises would keep them awake. These experiences were also repeated during the night:

“There were some nights that I just couldn’t sleep. I couldn’t sleep for night after night. I had sleeping tablets, they didn’t seem to make any difference. Then they moved me to a ward and then I started sleeping. I mean I wasn’t sleeping at all I used to watch the clock go round and round.” (Participant ID 4).

Participants were asked about whether they were offered and used ear plugs. For some this did help to some degree, but they were still able to hear sounds: for example nurses’ conversations, and therefore ear plugs never resulted in a good night’s sleep.

“You could hear them talking and they weren’t just talking, it was loud.....they were rabbiting on all the time.” (Participant ID 5)

Participant ID 5 suggested that headphones, perhaps with some soft relaxing music in the background may help. In contrast participant ID 1 talked about how the automated blood pressure cuff inflating intermittently overnight disturbed his sleep.

Naso-gastric feeding was also discussed. One participant (ID 5) did not eat food orally for many weeks and received his nutrition through a naso-gastric tube. This is a small narrow tube entering via the nostril and tracks down through the oesophagus to the stomach. ID 5 talked about how he never felt hungry or thirsty.

“Well I was never hungry or thirsty. I used to get a toothbrush or a swab and put it round and swill my mouth out. I did it myself.” (Participant ID 5)

Other participants also remembered having received food via a naso-gastric tube. Two participants found the method of securing the tube, taping it to the nose, to be very uncomfortable, and one participant actually developed a sore just inside the nostril:

“ ...it was taped to end of my nose. That really hurts that does. The way they would get the tape and wrap it around the tube and then stick it onto your nose. I suppose if you can use your hands and stuff it wouldn’t be so bad. If you can’t use your hands or you can’t tell nobody that that’s hurting you.” (Participant ID 3)

Other participants also found the naso-gastric tube very irritating, *'just dangling there'*. In fact participant ID 2 could not wait for the tube to be removed and tried to negotiate with the nursing staff about other ways of meeting her nutritional requirements with nutritional supplemental drinks. Eventually, patients will gradually begin to eat a simple and soft diet, but it does require them to eat with a tracheostomy tube in their throat and still attached to a ventilator. One participant (ID 5) said that swallowing this way was uncomfortable and that he was aware of the tube in his throat all the time. Two participants referred to toast as being particularly difficult to swallow (IDs 1 & 2). All the participants indicated that they had no appetite for long periods and that meal times were not anticipated favourably. The presentation of the food overall was good, they felt, but often did not feel hungry. Three participants indicated that their appetite did not return until they had left intensive care and were on a hospital ward.

All the participants were asked if was there any procedure or part of the day they particularly did not like and they all had the same response "suction". This is a procedure where a small tube is passed down into the lungs via the tracheostomy tube to remove sputum. Both nursing staff and physiotherapists will carry out this procedure intermittently throughout the day and night, as clinically indicated. Participants described how they found this procedure distressing as it involved feeling as if one was choking or wretching:

".....they would poke something in and it stops you breathing almost and then they tell you to cough. As you are coughing you can't breathe and they are trying to get the liquid out. That is painful, frightening, horrible, thing. When they do it once and

they can't get what they want they do it again straight away. That's really hard, that sticks in my mind." (Participant ID 3).

However, while all the participants found the procedure distressing, they also said that they found breathing easier after the procedure, gained some relief from difficulties with breathing and realised that it was necessary.

The participants' responses to their experiences regarding physiotherapy interventions were mixed. Most talked about getting out of bed and trying to stand up, with or without the help of a hoist, rather than breathing exercises. All but one of the participants appeared to have a good rapport with the critical care physiotherapist and liked the fact that he would visit them on the ward after they had left critical care to see how they were progressing. Participant ID 4 explained that he found getting out of bed with the help of equipment very difficult and he used to experience some chest pain. He would ask for help from the physiotherapist but the therapist would refuse indicating that he had to help himself. One participant (ID 5) referred to him as '*the butcher*', but also qualified this by saying that the term was a joke between them.

Participants' experience of personal care was associated with embarrassment, loss of modesty and dignity. The use of toilet aids, in particular, was disliked and were understood to be difficult to use. While participants generally liked having a wash there were concerns about lack of continuity of care, which exacerbated embarrassment. Rest periods were seen as being too busy, sleep often being disturbed and the environment being very noisy. While some participants did not like the

experience of having naso-gastric tubing secured with tape to their noses; the experience of suction was identified as the most disturbing nursing procedure of all.

Theme Four.

Asleep or awake? Vivid, violent, confusing and disturbing dreams.

When participants were asked to describe what they remembered of their experience in critical care, all described their dreams in vivid detail. All the participants were heavily sedated for a number of days during the very acute phase of their critical illness. From their accounts, it appears that it is during this time that the dreams took place. Indeed, when they woke up they all found it very difficult to distinguish between dreams and reality. All participants initially thought that their dreams had actually happened in real life and all experienced flashbacks. They described some of their dreams with other dreams were referred to but not described in detail as they were perceived to be too violent. These dreams also seemed different from usual dreams because they seemed so real to the participants:

“I can’t explain to you how vivid these dreams are. It really is that you have done it” (Participant ID 3).

“The dreams were as real as like I’m talking to you now. There were good ones and bad ones. The bad ones I’d rather not talk about they were frightening....this is only the second time I have talked about this....” (Participant ID 6).

Participant (ID 4) talked about a ferry journey to Ireland:

“I had some dreams people won’t understand unless they have been through it. Well it’s more than a dream, it’s actually living it completely where you can feel the water, and smell the air, and you are there. It’s so real when you come out of it all afterwards for a number of weeks, you question the whole thing. (Participant ID 4).

Once this particular participant’s condition improved, many weeks later, he began to ask his wife about the trip to Ireland in an attempt to establish whether or not it had really happened. Participant ID 2 was fearful for her family, as in one particular dream a man had deliberately run over his two children with a car and they later appeared to be dead in the accident and emergency department lying beside her.

All the participants indicated that they did not forget these experiences. Often it was only some time after the dreams that they felt more able to talk to family members about these disturbing dreams. This was considered a way of confirming that the events were just dreams and an attempt to try and make some sense of them. One participant (ID 4) also talked about how he became disorientated following a move from the intensive care unit to the high dependency unit. He indicated that he had dreamt that he walked to another part of the hospital to have his wound dressing replaced. When he woke up his family were present at the bedside and he wondered how they could have possibly found him. This episode confirmed, for him, how disorientated he had been.

While still sedated, participants experienced vivid, life like disturbing dreams that were often violent in nature. They were able to describe strange smells and tastes

within these dreams and the dreams also included photographs and pictures that were close to the beds that they were in. Dreams were so disturbing they felt they were unable to talk to other people then because of the violence and horror involved.

Theme Five: A noisy and disorientating environment.

It was difficult for each participant to pinpoint exactly when they first became aware of their surroundings and were sometimes confused by the dreams they experienced. Some participants talked about voices they did not recognise and some talked about how photographs or pictures on get well cards had appeared in their dreams. For participant ID 2 a door frequently appeared in dreams but it was also the actual door close to her bed space. This may suggest that although participants were not fully conscious they did have some awareness of their surroundings in the early acute phase of their critical illness. Furthermore, this awareness of surroundings is possible as it is current practice to interrupt sedation on a daily basis just long enough to allow a patient's conscious level to lighten. Once this has happened sedation is then recommenced. The rationale for this practice is to prevent sedative drugs accumulating in the body which may result in the patient taking an increased amount of time to wake up when clinically appropriate.

Participant (ID 3) discussed waking up in a large space, being on his own, and not being able to see other patients:

“A lot of the time I was facing the ceiling and I could see these round things I didn’t know what they were. I now know they were for the air conditioning, but I thought

other things...I thought I was in some kind of experimental camp. I remember the room being a lot of green'' (Patient ID 3).

In contrast, participant ID 4 believed he was located in a large warehouse:

“When I started to wake up everything was all over the place. I didn’t think I was in a ward, I thought I was in a big warehouse to start with. Yes, I couldn’t make it out. I was doing strange things, I was imagining things. I thought I was in a big warehouse, like a big type of holding store. Where they used to import type of things. When I woke up I thought this is a cold place to put me, I thought fancy putting me in here.” (Participant ID 4).

As the participants’ conditions improved so that they no longer required continuous sedation, they indicated that they were more easily able to recall more about their surroundings. However, none of the participants were particularly aware of the ventilator or the monitors, which would have been located behind them and not visible:

*“You can’t see behind you, and you don’t about the ventilator being there”
(Participant ID 2).*

“I didn’t know about the breathing machine, I didn’t know it was there”. (Participant ID 6.)

One participant (ID 1) could describe the monitor and the ventilator, but that was because he was positioned opposite another patient with similar equipment. All the participants commented on how noisy the critical care areas were, mainly because of the alarms from the different types of equipment. More importantly, equipment was left with alarms sounding for long periods of time on some occasions and two participants commented that they thought the alarms were ignored, on occasions. Participant (ID 3) found this particularly annoying:

“If an alarm was left, it would really annoy you. For some reason you would just focus on that noise and not on anything else.” (Participant ID 3).

However, none of the participants were aware of their own alarms making noise. I specifically asked about this possibility as I wondered if they were afraid when this happened and whether they were they given reassurance. However, they all said they did not remember their monitors alarm sounds.

Most participants could not see other patients as participant ID 5 reported:

“It was a big place, I was on my own. I couldn’t see anybody either side of me. All I could see was people washing their hands as they came in. That was the only link with outside world I got.” (Participant ID 5).

There was, however, some awareness by participants of other patients being close to them and they sometimes wondered and how ill their ‘neighbours’ may be:

“I think if I had seen somebody dead or dying in front of me, or be wheeled out dead, I don’t think I’d have coped as well I have. I think seeing someone die would have really upset me and made me more anxious and scarred. But thankfully I didn’t, I wasn’t aware of any of that.”(Participant ID 2).

In this theme findings indicate that a noisy, strange environment creates difficult feelings and unusual thoughts for participants but also a sense of isolation from other people. At times, the participants were unable to make sense of their surroundings, and these latter findings are linked to the sense of vulnerability and loss of control discussed within Theme 6.

Theme Six: Vulnerability, and loss of control over body, mind and identity.

In this theme findings are presented which indicate that participants experienced a powerful sense of vulnerability, but also, at the same time, a loss of control over their bodies, their minds and such experiences also influenced their sense of identity.

While this theme is drawn from all of the participants’ data, participants ID 3 and ID 4 expressed this sense of vulnerability and powerlessness more intensely than other participants. They were different from other participants in that they had been critically ill for a longer period of time than the other participants. For these two participants, when sedation was eventually stopped they experienced severe muscle weakness and were unable to move. Participant (ID 3) spoke at length regarding how helpless he felt:

“It starts from lying in bed and trying to look round the room and realising that I couldn’t move. I couldn’t move my fingers. I became frustrated that I could think and recognise things and people, but couldn’t move at all. Nothing at all and that was really hard to come to terms with. I didn’t know where I was for quite a while, I’m sure I was being told all the time, but it hadn’t sunk in, and I remember just lying and wherever my face pointed I could look, but apart from that I couldn’t look round. (Participant ID 3).

Participant ID 3 explained his limited view of his world was influenced by his position in bed in the intensive care unit:

“I remember like different sections of white boards, separating sections and green walls. But it seems whenever I was lying down I was always facing a wall or partition of some kind. So they would roll me one way and I would see the portable telly and the pictures of New York, and roll me the other way and I’d see the cards on the wall. If I was rolled on my back obviously I just saw the ceiling.” (Participant ID 3).

Later in the interview participant ID 3 also emphasised how incapacitated he was feeling:

“I think at that stage the way I was, was really more or less a vegetable, I could not do anything at all.” (Participant ID 3).

This participant also discussed his wife visiting, his not being able to speak and also feeling so weak he could not move:

“Meg would come and look at me...and slowly I would try and talk and she would try and lip read.” (Participant ID 3).

The expression ‘*would come and look at me*’ really captures this sense of mental and emotional isolation and vulnerability. Participant ID 3 confirmed this when he later talked about how, in his temporary incapacitated state, he lost his confidence and a sense of control over his body and mind:

“Basically you give your life to someone else to control and they decide when you eat, when you drink, they decide everything you don’t have a say in anything.”
(Participant ID 3).

Participant ID 4 talked about the fear associated with being unable to move his body, being unable to speak or even unable to attract others’ attention:

“It wasn’t very nice, especially when I couldn’t lift my legs, my arms or speak even. That was a frightening thing I couldn’t speak...I couldn’t attract attention because I couldn’t even lift my fingers, I could just wiggle my toes.” (Participant ID 4).

Indeed this participant, at one point, had the sense that some kind of conspiracy was happening to him and that deliberate actions had been taken to make him so vulnerable and powerless:

“And I was sure there was a conspiracy against me. That’s why I couldn’t move my arms, legs or speak. I thought they had done something to me, to take away all that so I couldn’t move.” (Participant ID 4).

Both participants ID 3 and ID 4 expressed their sense of frustration, anger, hopelessness and emotional isolation. For example, participant ID3 described how he was unable to express his emotions:

“The whole experience for me was really frustrating. I became angry inside, but I had to learn to deal with that really quickly because I had no way of expressing myself.” (Participant ID 3).

The sense of loss of control for these participants experiencing disturbing psychological and environmental experiences within critical care is important to emphasise. This sense of vulnerability and loss of control is associated with nurses actions, the environment, difficult feelings of helplessness, fear, frustration and, for one man, even a perception that a ‘conspiracy’ was afoot to ensure he had no control over his life or his body.

Summary.

The sense of loss of control for these participants, experiencing disturbing psychological and environmental experiences within critical care, is important to emphasise. Loss of control is also linked to the disorientating and noisy environment, within critical care, the difficult feelings associated with physical care provided by professionals, and the psychological challenges provided by losing one's voice. Trying to live with and communicate with others using an artificial device: that is with a tracheostomy tube inserted into their tracheas, compounded these difficulties. Communication allowed participants, through visitors, to establish some influence over their bodies, minds and feelings. Communication was, however, also fragmented particularly because of the loss of their voice. However, the central importance of the presence of family visitors in providing social support in an alienating, disorientating environment must not be underestimated when analysing participants' experiences.

These themes will now be considered again, in the light of previous research, and findings discussed in order to consider the implications for policy, nursing practice and future research.

6. Discussion.

This final section reviews this study's findings in the light of previous research with the aim of establishing its significance for the care of patients with tracheostomies receiving long term care in critical care units. In addition, there will be consideration of the importance of reflexivity focussed on the researchers' experiences within the research process, but also the impact of the relationship between the researcher and participants on the research process. Study limitations are also discussed, as are the implications for policy, nursing practice and future research. Some final conclusions are also drawn.

The centrality of family visitors' presence and social support within patients' critical care experiences.

It is important to avoid underestimating the extent to which participants' visitors are seen as such important assets for patients in this study in one intensive care unit, in the West Midlands in England. This is especially the case if participants are not to 'give up' on life and to help them with their determination to 'carry on' as Engstrom and Soderberg (2007) also found in Sweden. It was found that visitors serve as links with the outside world and links with participants' lives before admission to intensive care. The significance of this is that participants saw communication as extremely difficult; the environment as confusing; they experienced disturbing dreams and feelings and an almost overwhelming loss of control over their lives. In a sense, their visitors were able to convey the participants' identity and concerns to the healthcare professionals by acting as advocates for participants. Engstrom and Soderberg (2007)

also suggest that family visitors provide a link to the outside world giving a sense of hope that patients could, and would return to it, and identified ways that family visitors could advocate for patients. Interestingly, the findings presented here, as in McKinley's (2002) work in Australia, demonstrate that family visitors are key people who follow the patient's journey from the onset of illness to the experience within intensive care, and are also able to help patients piece together what has happened to them. This process enhanced the participant's sense of security and, as termed by Engstrom and Soderberg (2007), helped in 'validating their memories'.

This study's findings regarding the importance of family were in many ways surprising to the researcher, an intensive care nurse, particularly in light of how little importance nursing staff tend to place on visiting time. It was clear from all of the interviews, how vital the presence of the family was to all of the participants. In fact, from the perspective of the participant it was their family who met almost all of their needs and *not* nursing staff. Although each participant mentioned one or two particular nurses who had cared for them, generally the contribution of the majority of nurses was not significant. Generally, nursing staff were very much peripheral within participants' accounts about their time spent in critical care. In the early stages of a patients' time in intensive care, perhaps when the patient is critically ill, there may be, in my experience, some difficult conversations to be had with relatives. However, once patients are conscious and awake, but still requiring respiratory support from a ventilator, my experiential observations indicate that relatives may, at times, be seen as an inconvenience. Personally, in practice, I often thought that patients may need more rest and less visiting. However, this study found and confirmed earlier work by Hupcey (2001), that nurses' perceptions of the patients'

needs for social support are often underestimated and that nurses need to assess patients and visitors needs for social support more thoroughly. For the participants in this study, in England, it is visitors who play a key role in providing social support.

Losing your voice: unresolved communication difficulties.

Unsurprisingly, this study confirms Patak's (2004) work which reported that insertion of a tracheostomy is associated with communication difficulties. Indeed, the study findings also confirm Happ's (2000) findings, about patients' experience of 'voicelessness'. Findings reported here indicate that losing one's voice is associated with a sense of disempowerment and isolation, specifically being associated with being ignored in medical ward rounds. McKinley et al. (2002) found that patients do feel ignored as people and that the machines behind them are being treated rather than them. The findings in this study also identify how participants described being spoken about, rather than with, during nursing ward rounds in much the same way as during medical rounds. The communication methods attempted by participants, such as removing the oxygen saturation probe (with a resulting alarm sound), or banging a pen on the side of the bed were initiated by patients rather than nursing staff. Findings also indicate that there seemed to be no clear recognised method of communication developed by professionals, and hence participants often resorted to blinking their eyes or wiggling their toes. Furthermore, it was difficult for participants to express feelings, seek explanations or gain reassurance from healthcare staff.

As nursing staff, in practice, we know that such patients cannot shout or call if they need something, for example when a piece of breathing equipment becomes disconnected. However, my experiential observations indicate that there is no agreed method regarding communication with these patients and little about communication is documented. There is no structure built into the organization of care for a regular time for communication for these patients, which may account for one of the reasons why participants so looked forward to and enjoyed visiting time by relatives. It appears that they were the ones who could help them to meet their individual needs and ask for simple but important things.

Alasad (2004), found that nurses' communication could be ineffective or inconsistent as my own study certainly did. Furthermore, Ashworth (1981), found that nursing communication could depersonalise patients, in that they are not treated as individual personalities, which findings here also confirm. This may be because, as Leathart (1994) has speculated, limited communication by nurses also helps them insulate themselves from anxiety and stress. However, such findings are beyond the scope of this study. Within my role as professional development nurse within intensive care I am also aware that nurses new to intensive care, with concerns about the uncertainty and complexity of practice and procedures, may disengage from patients as they concentrate on technical medical processes.

Joblanski (1994) and Patak (2004) have both suggested that nurses may be communication *gatekeepers* and control the type of experience that patients have in intensive care. The use of speaking valves were very valuable for patients, in this study, in that they enabled them to communicate with their relatives more effectively

but, interestingly, in this study none of them referred to its use as an aid to communication with healthcare workers. In addition, the use of the speaking valve is contradictory within this particular critical care environment as the participants used it exactly as it is primarily intended: that is, as a means of communication. Whereas, the medical staff and nursing staff used the device as a method of assessing a patient's breathing capability without a ventilator. It was the participants' relatives, in particular, who enabled them to attempt to overcome 'voicelessness'. No participant mentioned the value of the speaking valve in terms of talking to the nursing staff and telling them what they needed. Indeed, one patient was using the valve when visitors attended and he would then ask for it to be removed! This may have given a wrong impression to the medical and nursing staff in thinking that he could only tolerate the valve for short periods at a time, when, in fact, he said that for him it was a communication tool rather than a weaning tool.

Difficult thoughts and feelings associated with physical, personal care by health professionals.

The experience of personal care was associated with embarrassment, loss of modesty and loss of dignity. The use of toilet aids, in particular, were disliked and were perceived to be difficult to use. While participants generally enjoyed having a wash there were concerns about lack of continuity of care, which exacerbated embarrassment, on some occasions. These findings correlate with Billings (2009) work, who identified that dignity was preserved when individualised care was given consistently and discretely by the same person. In this study, the lack of continuity in providing personal care by nurses was unhelpful for participants.

In my experience of intensive care nursing, personal and essential nursing care can be perceived as less important by some nurses than some of the technical tasks required of nurses. However, for the participants, the importance of delivering personal and essential nursing care in a way that considers and maintains a person's dignity and modesty is paramount. Lawler (1991) found that some nursing procedures do cross social and cultural boundaries, by doing things for people they would do for themselves if they were able. While such processes may be routine for many nurses, the uniqueness of the experience for individual patients should never be overlooked by nurses. Despite raised awareness (DH, 2001) and indeed nurses' professional obligations (NMC, 2008) to ensure patients feel they are treated in a dignified manner; it appears that within critical care that this, at times, may be overlooked.

While participants in this study, did not like the experience of having naso-gastric tubing secured with tape to their noses, they understood the necessity of the naso-gastric tube for supplemental feeding. In contrast, some participants discussed the difficulties of eating and swallowing with a tracheostomy tube in place.

Furthermore, all participants identified the experience of suction into their lungs, via a tracheostomy tube, as being the most disturbing nursing procedure of all. Although participants acknowledged the benefits of secretions being removed from the lungs, the suction procedure was the one they dreaded most of all. These findings are consistent with Sherlock's (2009) recent work.

Asleep or awake? Vivid, violent, confusing and disturbing dreams.

Findings here indicate that, while still sedated, participants experienced vivid, life like and disturbing dreams that were often violent in nature. They were able to describe strange smells and tastes within these dreams and the dreams also included images and pictures that were close to the beds that they were in. Dreams were so disturbing that they felt that they were unable to talk to other people about them because of the violence and horror involved. Although I was aware, before the study, that some patients experience disturbing and disorientating dreams, I was shocked when interviewing participants at how prominent such dreams had remained within their memory of being critically ill. Indeed during the initial stages of each interview, when participants were asked to relay the story of their experience of being on an intensive care unit, the vivid life like dreams they had encountered was one of the first subjects all the participants discussed. It could be that participants were trying to relay their experiences in a chronological order, as such dreams are thought to occur on the threshold of being aware while sedation is reduced or discontinued (Laitinen, 1996,). However, the length of time participants took explaining their dreams, the detail and sometimes depth of emotion displayed is important to emphasise. The potential power and influence of these dreams or unreal experiences was evident and could have prolong effects on the emotional well being of patients who have been critically ill as Granberg (1999) has suggested.

Some patients' do experience flashbacks and nightmares long after they have made a full physical recovery and develop symptoms of post traumatic stress disorder (Jones et al., 2004). For the participants in this study, they all requested reassurance, from the researcher, that their experience of such dreams was not unusual. Although participants had eventually understood that their unreal experiences were dreams, for

some it had taken a considerable length of time to realise this. Initially, because participants were unable to speak and seek reassurance, this had impeded their ability come to terms with these experiences. Perhaps nursing communication, education and reassurance being offered early to patients and relatives when sedation is discontinued, could provide patients with the opportunity to discuss such dreams and prevent potential psychological problems? Currently, there are limited or no resources within many NHS hospital trusts within the UK to provide follow up rehabilitative psychological care. However, recent NICE Guidelines (2009) do seek to address this, although funding for such services may remain a challenge. Fortunately, within our trust we recently introduced a new 'follow up' counselling service for patients who have been discharged from intensive care which is a valuable development.

Awake or asleep? A noisy and disorientating environment.

The findings indicated that all the participants had difficulty sleeping during their stay in critical care, and although there may be many contributing factors, the participants cited noise levels as particularly problematic. Baker (1993) found that the noise from alarms in critical care reached 70 dB(A) which is akin to heavy traffic noise. Disturbingly, a recent audit carried out within the intensive care setting where this study was undertaken, found that noise levels were high and that alarms were still reaching a level 70 dB(A). Most of the participants also found it difficult to sleep despite the use of sleep medication. This finding is similar to that of other studies where patients have found it difficult to regain their natural circadian rhythms following the use of benzodiazepines which can compound sleep disturbances and

other sedative-hypnotics and analgesia which can reduce sleep, resulting in a lighter sleep (Dines-Kalinowski 2002).

None of the participants indicated that ear plugs were an effective way of blocking out unwanted noise, which contradicts the findings of Wallace (1999). However, it would be appropriate to pursue the trial of different brands of ear plugs in the future, as those in current use may not be most useful. All the participants were aware of a protected time each afternoon, for rest, but it appears often they were unable to rest due to noise or activity. The benefits of a dedicated rest period have been acknowledged at an organisational level, however, from my experience in practice, this policy is not always adhered to.

One participant commented on his experience of sleep disruption related to the frequency of recordings taken about him during the night and, in particular, questioned the necessity of frequent blood pressure readings, in particular. This concurs with Tamburri's (2004) findings which indicated that the frequent and repetitive nature of care left little opportunity for patients to sleep.

While disturbing dreams are important findings to emphasise, a noisy strange environment also created difficult feelings and unusual thoughts for some participants as well as a sense of isolation for some. Participants suggested that they could not see other patients and they talked about being on their own in a large space. Sometimes seeing the use of a door or a sink provided them with the only evidence that there were other humans being around (as they saw others walk past these objects).

Vulnerability and loss of control over body, mind and identity.

Christensen and Hewitt-Taylor (2007) have emphasised how the concept of empowerment has challenged a traditional paternalistic approach to healthcare and, within intensive care, how this process is particularly challenging in restoring control to people in an alien and possibly alienating environment. Findings here confirm that the sense of loss of control, alongside disturbing psychological and environmental experiences within critical care, are important for patients . This sense of vulnerability and loss of control is associated not only with the criticality of a medical condition, but also has strong links with nurses' actions and attitudes (Wahlin, 2006,). These factors are compounded by nature of the environment, difficult feelings of helplessness, fear, frustration and, for one participant, even a perception that there was a 'conspiracy' to ensure he had no control over his life or his body.

These findings, in particular, shocked me as a nurse. I am left with a concern for the overwhelming sense of vulnerability and powerlessness experienced by patients who are so dependant and so vulnerable when connected to machines, but also in the power of healthcare workers. The overwhelming sense of isolation is striking especially when each patient has a nurse allocated to care for them 24 hours a day. Within my role as a practice and professional development nurse, I now recognise a void within the content of training currently offered to critical care nurses within the department where a focus on the psychological needs of the critically ill is overlooked. There is, within my hospital trust, a policy for vulnerable adults, specifically for people who cannot speak and advocate for themselves, such as people with dementia or with learning difficulties. However, here is a group of patients,

conscious but unable to move or talk, but with no policy or procedure to address their needs in this respect. This issue will be addressed within the recommendations listed later in this chapter.

Wahlin (2006) found that, within critical care, patients may prioritise having control over physical comfort and hygiene, rather than decisions about complex treatments. This study also found that participants emphasised the importance to them of influencing the delivery of their day to day care, plus, again, access to and communication with their families.

Researcher reflexivity.

The positionality of the researcher within the research process is important here, because I was not an outsider employed by another organisation to undertake this research. I was an insider, a nurse who also worked within the intensive care unit from which participants were later recruited. I was not providing care directly to any participants, as I was supervising others providing that care. I hoped participants would be more able speak as freely as possible when I interviewed them because I was not directly involved in their care. To an extent, whether they were able to talk as freely as they would have liked is uncertain, because I remain a nurse and manager, and have power and influence within the unit and hospital organisation. However, findings do suggest that participants did think and talk critically about their experiences, and my insider status also enabled me to have insights into the nature of the intensive care environment. I was able to facilitate them to talk about their experiences. However, as this discussion has emphasised so far, and as discussion of

implications for policy and practice will shortly confirm, my personal and professional motivation is to improve the quality of care for such patients and overcome some of the limitations within nursing care, that are identified within this study.

Limitations of the research study.

Any study has limitations, as the previous discussion of positionality has suggested. The small number of participants interviewed within this exploratory qualitative study limits the scope for transferability as the sample may not be representative of diverse patient groups, for example when considering gender, age, ethnicity and religion. However, this study intended to examine and analyse patients' experiences when nursed within a critical care environment, while conscious and attached to a mechanical ventilator. It can be argued that because the participants in this study were interviewed before discharge home from hospital, they may have been generous in their accounts of their experience of time spent in critical care. Furthermore, I chose not to check the validity of findings with participants as I did not wish them to be further inconvenienced, because one of the participants later died and another was transferred to another hospital trust for major surgical procedures. The validation of findings and a more participatory process of research is intended in the design of a grant application for a wider study, building on this study's findings, in the future.

Participants were interviewed in hospital as the researcher wished to investigate their experience whilst it was still fresh in their memory. The specific value of qualitative research in enabling participants to tell their own stories, is evident here, I would

suggest. Indeed, the value of the qualitative approach undertaken is reinforced by important unanticipated findings about patients' dreams, the extent of isolation and loss of control, how peripheral nurses are to participants' experience, and the centrality of visitors in their lives. All such findings emphasise the value of this qualitative research method and design.

Implications for policy, nursing practice and future research.

Practice: nursing.

Throughout the fieldwork and the process of data analysis I have been struck by how little participants had to say about nurses and how peripheral most of the nursing staff were to the patients' experience. Each participant spoke about individual nurses, but they appeared to feel that nursing activity was instrumental and focussed on particular tasks. Indeed, there is little evidence from their stories to indicate that nurses, in general, were engaged with them face to face, as people. Nurses were seen as being efficient, but the demonstration of compassion I hoped for as a nurse and researcher was not evident from participants' stories. One of the key implications of this study is that it is possible and necessary to build upon previous research. of Wahlin (2006), in particular advocates the promotion of reflexivity by nurses about power in relationship with patients and the need to prioritise engagement; understanding of patients' views and motivation; stimulation of patients and promoting of their self esteem. These findings also emphasise there are important potential allies in such processes, that is patients' relatives. Wahlin (2006) found that patients felt safer when close relatives were in proximity, which should not be

surprising, but this issue needs to be emphasised if the nursing profession is serious about engagement and empowerment.

The importance of reflexivity about medicalised power and the associated biomedical model, within intensive care is not to be underestimated and nurses, in particular, can help patients and relatives by seizing on the opportunity to act as advocates with them. 'Weaning', the researchers' early conceptual concern, was *not* important to participants but family certainly was. This study, unlike previous qualitative studies, investigated the specific experiences of patients who had spent long periods of time in intensive care, the minimum stay being 21 days, with 3 participants staying over 50 days and the maximum stay being 61 days. These patients endured and lived with debilitating and disturbing experiences for weeks and months on end. Undertaking qualitative research was an important, if limited, way of overcoming my own limitations and of informing this critique of medicalisation (Conrad, 2005).

Furthermore, this study provides a critique of our power over very vulnerable human beings in order, ultimately, to improve the quality of future patients' lives within intensive care. Knowledge/power as identified by Foucault (1977) and medicalisation, as identified by Conrad (2004) and others, is always resisted as Bury (2005) has argued. Findings here indicate that patients and relatives will seek connectedness in spite of professional power within the intensive care setting. Findings also show that there may be a discrepancy between what patients' value and what nurses, focussed on the observation 'chart', may prioritise. Patients' were empowered by their families who provide an opportunity for nurses to recognise and support them but also allows nurses and other healthcare professionals to think and act critically regarding medical knowledge/power.

Practice: routine of daily care within nursing

While engagement and empowerment are important process issues to address, it is clear that relatively simple instrumental tasks like going to the toilet and having a wash are extremely important experiences to patients and can cause emotional distress and feelings of disempowerment. It may be necessary to investigate alternative solutions for faecal collection and consider practice in other areas that can offer guidance. . . In addition, it is essential to review nursing interruptions, day and night, which may deprive patients of sleep and consider, for example, the use of head phones, rather than ear plugs, as suggested by one patient, or even changes to how blood pressure cuffs left on patients arms all of the time. Furthermore, noise levels within critical care need to be addressed, with specific attention to alarm volume levels on equipment and monitoring devices.

It is also worth considering, in practice, what can be done about suction of endotracheal tubes and tracheostomies which was the most distressing procedure for participants. Further training is needed to help nurses prepare patients to cope with and prevent their stress when such traumatic procedures are undertaken, such as talking through the processes in detail., Such training, at least, must emphasise how distressing these procedures are for patients. Another important issue to emphasise is that of the patients' positioning within the physical space of the unit: can patients be positioned in such a way to orient them to their environment? This issue needs to be reviewed when findings are disseminated to staff and managers.

What these findings also confirm is that the methods chosen for this study are similar to the methods necessary to undertake excellent nursing, in the sense that good active listening and communication are essential in practice, as well as research. The routine tasks undertaken by nurses may seem relatively minor issues compared with, for example the drama and complexity of resuscitation, within a highly sophisticated technical environment. What is clear is that induction, education and training cannot take for granted the importance of psychological care and communication as being integral in providing physical care. In this respect the deconstruction of medicalised knowledge and power is necessary to empower nurses in order to ultimately act as empowering advocates for and with patients and relatives. These concerns are not just abstract theoretical concerns but also concrete issues to be addressed if we are to avoid the iatrogenetic effects of our practice on patients' wellbeing, as identified by Illich (1976) and others.

Practice: communication by professionals.

The alienation, isolation, fear, anxiety, difficult feelings, disturbing dreams and sense of powerlessness at the heart of participants' experiences, again emphasise the importance of effective communication by nurses to promote mental and psychological well being. While communication will now be structured into training and education for intensive care nurses by my professional development team, it may be that lip reading training is also required and it will be suggested to colleagues that such processes need to be specified explicitly within plans of care. In addition, it may be necessary to devise an alternative risk register, that is a register to identify psychological risks associated with communication within this group of patients.

The Passe Muir tracheostomy valve is often used to enable patients to be weaned off the use of a ventilator, its successful use being an indicator, medically, that weaning is being successful. However, the valves' use for communication may be seen as being of secondary value for professionals which is certainly not the case for participants here. Clarification by all intensive care health care staff of the function of this technology is essential.

Practice: medical rounds by doctors and nurses.

Further clarification of the function of doctors' rounds for patients is required. Why is it that so little time is spent speaking to the patient, when in another environment, such as an outpatients department, such practices would be unacceptable? This area clearly needs further research, but consideration of study findings within our unit is required. For example, should nurses manage these encounters and explain to the patient from the beginning to the end of the encounter? Equally, the purpose of nurses' rounds also needs clarification and improvement. As the key individuals within the process of care, nurses can lead on improving inclusive communication within our encounters with patients using simple but important effective communication. This could include simple strategies for using call buttons or sensitive pads for patients to use to attract attention.

Policy implications.

This was a small study, so the main implication of findings here are that local policy makers and policy implementers within intensive care should be informed of the study findings, and that the professional development team, including myself as a member of that team, can ensure that new policies be informed by findings. However, the study does emphasise the disturbing patients' experience of disempowerment, within a technical, medicalised environment and culture, which must reinforce the importance of national policy emphasis on patient involvement, dignity, compassion and respect for patients (Darzi, 2008, DH, 2010), and the follow up care of such patients (NICE 2009).

Recommendations.

- Develop a local nursing care strategy, with colleagues and participants, that addresses the specific and holistic needs of intensive care patients who have been weaning off ventilators or a long period of time, by June 2011.

Dissemination

- Study findings have been presented to the intensive care managers, the professional development team, nursing and medical staff.
- Within my current professional development role, use findings to inform future teaching, training and simulation for nurses.
- Findings presented to the West Midlands critical care research network.

- Produce a two page summary for study for participants, all nursing and medical staff, and for the west midlands critical care network.
- Submit a paper to a peer reviewed journal (Critical Care Nursing) and also submit a paper to a well read accessible journal (Nursing Times).

Future research

This study confirms the particular value and need for qualitative research approaches to enable examination of participants' experiences of critical care if we are gain access to their views and experiences and unanticipated findings. Therefore the following will be undertaken:

- Seek funding for a larger wider qualitative and quantitative study. The focus will again be on patients who are conscious and connected to a ventilator, but will include a range of intensive care units, and a sample to include patients of diverse socio-economic, ethnic, and nationality backgrounds, and other actors including relatives, friends and professionals. The overall goal, in relationship to benefit for patients, will be the development of a holistic evidence based nursing protocol which specifically addresses the psychological and physical needs of patients in intensive care.

Conclusion

Although this dissertation reports on a small exploratory qualitative study, important learning can be emphasised. Qualitative semi-structured interviews with 6 participants enabled investigation of the experiences of patients nursed within a critical care environment, over a long period of time, when conscious and attached to a mechanical ventilator. A particular advantage of qualitative research is that it produced findings that confirmed previous work but also produced unanticipated findings and challenged earlier study goals concerned with ‘weaning’ a process that was insignificant to participants. Thematic analysis produced data which emphasises the centrality of family visitors’ presence and social support within patients’ critical care experiences, the disturbing effects of losing one’s voice and the difficult thoughts and feelings associated with personal care. In addition, participants experienced vivid, violent and confusing dreams within a noisy and disorientating environment. Together these experiences created a deep sense of vulnerability and a sense of loss of control over mind and body that is disturbing.

Findings have been discussed in order to identify implications for further research, which is necessary to build on this study. The significance of this study for local policy and nursing practice needs to be understood, not least in relationship to the importance of effective communication with patients when they have tracheostomies. Indeed, most crucially, recognition of a potential partnership between nurses, family visitors and patients is essential, especially focussed on enabling advocacy and social support for and with long term critically ill patients.

Appendix 1

Interview Questions.

Consistent with an interpretative and qualitative study, participants will not be expected to respond to a structured series of questions, within a rigid schedule, but will be enabled to talk about their own experiences, within three phases. Phase one is a key generative question, which is intended to enable the participant to tell their own story in their own words. The second phase of the interview is a series of potential prompts, which are intended to enable the participants to talk about experiences they may not have discussed in the first phase. The third and final phase includes some final conceptual questions, which will be used only if the participants have not talked about these topics in the first and second phases.

Phase One: generative question

I would like to hear your story about the experiences of being a patient in an intensive care unit. The best place to begin would be to tell me when you first became aware of being in an intensive care unit.

Please begin as soon as you are ready.

Phase Two: prompts regarding specific experiences.

Please tell me about having a tracheostomy tube in your throat?

Please tell me about not having a voice and not being able to talk?

Did you have a speaking valve? If so how did being able to talk make you feel?

Were you encouraged to eat a soft diet, for example mince and mashed potato?

Can you tell me what it was like when swallowing with a tracheostomy tube in place?

Did you look forward to meal times?

A team of nurses were allocated to care for you during your stay on the intensive care unit, did you feel that the nurses understood your individual needs.

Did you know what the plan for care was each day?

Did you feel involved in the planning of your care for each day? If not, how did you feel?

What elements of the daily routine did you like?

Which element of the daily routine would you have liked to change?

Each day on the intensive care unit there is an allocated rest period in the afternoon.
What was your experience?

What was your experience of sleeping at night on the intensive care unit?

When the ITU doctors came to see you each morning, could you hear what was being said?

Did they involve you in the discussion or explain to you what had been said? What did you feel about that?

Did you think that your progress was being checked by doctors during the day?

If you experienced pain or discomfort how did you make the nursing staff aware?
How was your pain eased?

During your stay in ITU how were you helped to pass the time?

How important was visiting time to you?

How did having your family and friends around you help your recovery?

Phase 3: conceptual questions

Were there any times when you felt anxious?

What circumstances made you feel anxious?

Could you describe to me how that felt.

What or who helped to calm you?

Did you feel in control of what was happening to you?

If you did not feel in control, then who was in control?

What is it like to be dependant on a breathing machine?

Throughout your stay in ITU did you think you were given enough privacy?

Do you think you were treated in a dignified manner?

Appendix 2

Date:

Title or Project:
Patient Experiences of Critical Care, an exploratory study

Name of Researcher: **Carol Drugan**, ITU sister.

Dear

My name is Carol Drugan. I am a nurse undertaking a Masters degree at Coventry University. As part of this degree I am doing a research study. In my research study I am trying to find out about patients' experiences of being weaned from a ventilator.

I am inviting 6–8 patients to be interviewed by me, regarding their views about this issue.

I am contacting you because you have recently been discharged from the intensive care unit, and I would like to invite you to participate in the study. It will require you allowing me to interview you for approximately an hour.

You will find an Information Sheet attached to this letter. This provides detailed information about the study. Please read the information sheet to see what is involved. I will contact you in two days time to see if you wish to be interviewed.

Thank you for considering taking part in this study.

Yours sincerely,

Carol Drugan
(Nursing Sister
Critical Care Dept.
Tel: 0121 424 3419

Appendix 3

Research Participant Information Sheet

Version 2. (16/01/2008)

I would like to invite you to take part in a research study I am undertaking as part of my Masters degree. Before you decide it is important for you to understand what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you have any further questions or are unsure about anything then please contact me to discuss it further before making your decision.

What is the study called?

Patient Experiences of Critical Care, an exploratory study

What is the Purpose of this Study? What is it for?

The purpose of this study is to find out what it is like to be a patient nursed within a critical care environment for a period of greater than two weeks, attached to a breathing machine with a tracheostomy.

Why have you been invited to be interviewed?

You are invited to take part as you have recently being a patient in the critical care unit for a period of greater than two weeks and had a tracheostomy.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time (including during the interview) without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your treatment or standard of care in any way.

What will happen if I take part?

The interviewer will arrange a suitable time and place to interview you while you are still in hospital. It will involve you telling the interviewer what it was like being a patient in an intensive care unit, from the time when you were awake and aware of what was happening to you. It is important that you tell this in your own words.

Towards the end of the interview a variety of questions may be asked if the interviewer wishes to explore further your experience as a patient in the intensive care unit. With your permission the interview will be tape recorded so that the interviewer can listen to you and not have to take notes. The tape recorded interview will be typed up and any personal details which could identify you are removed. The interview should last approximately an hour. Once the taped interview has been typed up you will be given a copy to confirm accuracy.

What are the possible risks of taking part?

There are no perceived risks to taking part.

What if I become distressed during or following the interview process?

If during the interview you find recalling your experience distressing, then the interview will be stopped immediately and you will have a choice whether or not you wish to continue. The researcher will stay with you to discuss any issues you may have. Should you become distressed following the interview, the researcher will be available to discuss any issues you may have. Furthermore, a visit from the critical care outreach nursing team and/or The Patient Advisory Liaison service would be arranged to provide further support.

What are the possible advantages of taking part?

The advantage of taking part for you might be that it provides you with an opportunity to discuss your experience in an open forum. Although research has been done before exploring the patient experience in critical care, treatments and technologies change frequently. Therefore the advantage staff to have a greater understanding of what it is like to be patient in critical care in the twenty first century.

How will my part in the study be kept confidential?

The study will not include your name or your hospital patient identification number. Direct quotes from interviews may be used in published material. However, such quotes will only be used to demonstrate a point the researcher is trying to emphasise, and will not in any way be used in a manner that would identify you as an individual. Furthermore, your experiences will not be directly used as examples in such a way that it would identify you. The interviewer will transcribe in a typed format the interview and no one else will have access to the tape or the typed interview. Once the interview is completed the tape will be stored in a locked draw, within a locked room. The tape will be destroyed once the interview has been typed up. The typed copy of the interview will be kept on a password protected computer. All data will be destroyed once the project is completed.

Complaints

Please note that the purpose of this research study is not to provide a forum in which to raise complaints about your time spent in critical care. The Heart of England Nhs Trust has procedures in place in which to deal with such issues. The interviewer can give you information regarding the complaints procedure, but the interviewer will not follow up complaints on your behalf.

If a matter is disclosed which the interviewer considers unacceptable practice, the interviewer will be duty bound by the N.M.C. Code of Professional Conduct to report this to the Critical Care Management.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect you safety, rights, wellbeing and dignity. This study as been reviewed and given favourable opinion by Sandwell and West Birmingham Local Research Ethics committee.

What will happen to the results of this study?

The findings of this study will be fed back to the Critical Care department, and may be published in a nursing/critical care journal. Furthermore the researcher intends to write up the findings in an appropriate format for the award of Masters degree at Coventry University.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. Please contact Carol Drugan on 0121 424 3419. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Who can I contact for further information?

Carol Drugan
Intensive Care Nursing Sister
Heart of England Foundation Nhs Trust
Bordsley Green East
Birmingham
B9 5SS

TEL: 0121 424 3419

Supervisor:

Dr. Margaret Goodman

Department of Health and Life Sciences
Coventry University
Priory Street
Coventry
CV1 5FB
Tel: 024 7679 5932

Patient Advisory Liaison Service (PALS)
Heart of England Foundation Nhs Trust
Bordesley Green East
Birmingham
B9 5SS
Tel: 0121 424 1212

Appendix 4

Research Participant Informed Consent Form
Version 2. (16/01/2008)

Title of Project:

Patient Experience of Critical Care an exploratory study.

Name of Researcher: Carol Drugan, ITU sister

Please INITIAL
Box

- | | |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without medical care or legal rights being affected. | <input type="checkbox"/> |
| 3. I agree to the interview being tape recorded, for the purpose of transcription. | <input type="checkbox"/> |
| 4. I understand that direct quotes maybe used in published material at a later date. | <input type="checkbox"/> |
| 5. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records. | <input type="checkbox"/> |
| 6. I agree to my consultant being informed of my participation in the Study. | <input type="checkbox"/> |
| 7. I agree to take part in the study. | <input type="checkbox"/> |

Name of Patient	Date	Signature
Name of Person taking consent (researcher)	Date	Signature

Appendix 5

Date:

**Consultant Notification Letter
Version1. (9/11/2007)**

Title of Project:
Patient Experience of Critical Care, an exploratory study

Dear

Name:

PID:

This is to inform you that the above patient has agreed to participate in this research study. This research is sponsored by Coventry University as part of Masters by Research Programme. The purpose of the study is to find out what it is like to be a patient in an intensive care unit for a period of greater than three weeks attached to a ventilator for respiratory support with a tracheostomy.

Data will be collected by conducting a one hour taped interview with the participant. The research process can be terminated at any time, and support mechanisms are available should the participant be uncomfortable during or following the interview process.

Yours sincerely

Carol Drugan
Nursing Sister.
Tel: 0121 424 3419

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